Prevalence and associated factors of caregiving burden among caregivers of individuals with severe mental illness: A hospital based study at St John of God Hospitaller Services in Mzuzu, Malawi.

By

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Declaration

I, *Richard Banda*, hereby declare that the work of this dissertation/thesis is my original work (except where acknowledgement indicate otherwise) and that neither part of it nor whole has been, or is being, or is to be submitted for any other awards or other purposes at University of Cape Town or any other higher learning institution.

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Dedication

This work is dedicated to my lovely wife Pauline and daughters Nellie and Promise. You are such a wonderful family and I am blessed to have you all.

Abstract

Background:

Severe mental illnesses (SMI) cause significant impairment for those living with the illnesses and often rely on caregivers for the ongoing care. Available evidence suggests that individuals responsible for caregiving may get distressed due to the caregiving experience, a phenomenon researchers call caregiver burden. Following the shift to community-centered mental health services, several studies on caregiving burden have been conducted in high income countries (HIC). However, there remains scarcity of data on the subject in Sub-Saharan Africa including Malawi. Therefore, the present study investigated the prevalence and associated factors of caregiving burden among caregivers of individuals with SMI at St John of God Hospitaller Services (SJOGHS) in Mzuzu-Malawi.

Methods:

The study adopted a hospital based cross sectional study. Recruitment took place at two outpatient departments of SJOGHS. Informal caregivers who were 18 years and above were asked to participate. The study recruited 139 caregivers and two research assistants approached participants at the waiting area. Caregivers who gave consent were asked questions about their caregiving activities using the Zarit Burden Interview (ZBI) (maximum score, 88). Data analysis was done using frequency distributions and descriptive statistics. The study used non-parametric tests such as a chi-square on all categorical measurements to test associations between variables and parametric tests such as t test on all continuous variables. The unadjusted and adjusted associations between socio-demographic factors and caregiving burden was conducted using logistic regression models.

Results:

On average, most caregivers experienced mild to moderate caregiving burden on the ZBI score (31.5 ± 16.7). In the adjusted model after controlling for caregivers' gender, caregivers' age, level of education, social support, care recipients' age and care recipients' gender, only caregivers' age, social support and care recipients' age remained significantly associated with caregiving burden. Older caregivers were more likely to experience caregiving burden than younger caregivers (OR=1.03, 95% CI 1.00-1.06), caregivers with social support were 71 % less likely to develop caregiving burden than those without social support (OR=0.29, 95% CI 0.14-0.62) and caregivers of older care recipients were less likely to experience caregiving burden than those of younger care recipients (OR=0.26, 95% CI 0.11-0.64).

Conclusion:

Even though the caregiving burden found in this study was low compared to other previous studies in some arguably developed countries such as Iran and Turkey, it remains high in other developing countries such as Ghana and Nigeria. The low burden in this study, could be attributed to several factors and context in which the study was conducted. One such factor is the routine psychoeducation that the hospital often conducts for caregivers during the subsequent monthly reviews of their care recipients. An important follow up would be to investigate caregiving burden among caregivers who are unable to access the services at SJOGHS. The results of this study are important to guide policy in the formation of effective community programs that may assist mitigate the burden of informal caregivers. Finally, to understand the importance and implications of informal caregiving, further studies are needed in Malawi.

Key words: *caregiving burden, schizophrenia, psychosis, severe mental illness.*

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List of abbreviations

ADL	Activities of Daily Living
CDC	Child Development Centre
CMD	Common Mental Disorders
DALYs	Disability Adjusted Life Years
HIC	High Income Countries
HREC	Human Research Ethics Committee
LMIC	Low and Middle Income Countries
MNS	Mental, Neurological and Substance use Disorders
NCDs	Non-communicable diseases
NGO	Non-Government Organization
NHSRC	National Health Sciences Research Committee
QOL	Quality of Life
SJOGC	St John of God Centre
SJOGHS	St John of God Hospitaller Services
SMI	Severe Mental Illnesses
UCT	University of Cape Town
WHO	World Health Organization

Definition of key terms

Caregiving burden: These are negative consequences that caregivers encounter when providing informal care to their care recipients with SMI. The effects may be in form of physical, psychological, emotional, social and practical challenges.

Care recipient: This is an individual living with a SMI, receiving care from an informal caregiver.

De-institutionalization: This is the process in which individuals with SMI are moved from mental health institutions to the communities for their treatment.

Informal caregiver: This is a person who provides unpaid care to an individual who is not able to care for himself/herself due to severe mental illness (SMI). The person providing care may be an acquaintance, friend or relative.

Serious Childhood Mental Illnesses: These refers to any serious mental health related problems that children and adolescent are suffering from.

Severe Mental Illnesses: These are serious mental disorders that cause impairments in the level of function of an individual living with the illness. Examples include: Schizophrenia and related disorders, bipolar disorders, major depression and serious childhood Illnesses.

CHAPTER ONE: INTRODUCTION

1.1 Context

There is a high prevalence of mental, neurological and substance use (MNS) disorders globally (Steel et al., 2014). For example, the World Health Organization (2004) reported that over 450 million people across the globe had MNS disorders. Depression alone is predicted to become the biggest social and economic burden in many countries (Flisher et al., 2007; Perlick et al., 2016). Current trends indicate that depression, alcohol use and psychosis are among the top 20 leading causes of disability worldwide, with depression accounting for 7.5% of all years lived with disability (Del-Pino-Casado, Frias-Osuna, Palomino-Moral, & Pancorbo-Hidalgo, 2011; WHO, 2017). Although epidemiological studies indicate variations in the distribution of these diseases, a high prevalence is reported to be found in low and middle income countries (LMIC) (Armstrong et al., 2013; World Health Organization, 2004).

In addition to disorders due to substance abuse and common mental disorders (CMDs) such as depression and anxiety, mental disorders also include SMI. Although literature demonstrates little consistency in defining SMI (Wiersma, 2006), other studies define SMI in three dimensions: first, an individual must have a diagnosis of a psychotic disorder not explained by a medical condition, secondly, the period of treatment for the condition should be two or more years, and thirdly, there must be an impairment in one or more of the following areas: psychological, social or occupational functioning as measured using the global assessment of function scale (Jeon, Brodaty, & Chesterson, 2004; Ruggeri, Leese, Thornicroft, Bisoffi, & Tansellaella, 2000). In addition to causing significant functional impairments, individuals with SMI may require hospitalization and psychotropic drug treatment (Jeon et al., 2004).

While a number of studies have investigated the prevalence of CMDs (Herman et al., 2009; Stein et al., 2008), few have reported on the prevalence of SMI (Kessler et al., 2009; Vigo, Thornicroft, & Atun, 2016). For instance, a systematic review on the prevalence of schizophrenia drawn from 46 countries found the lifetime prevalence of the disease to be 4%, contesting the frequently cited estimate of 1% (Saha, Chant, Welham, & McGrath, 2005). Examples of SMI include: schizophrenia and related disorders; bipolar and affective disorder; major depression, and serious childhood mental illnesses (Del-Pino-Casado, Frias-Osuna, & Palomino-Moral, 2011; Jeon et al., 2004).

A growing body of evidence shows that SMI continues to cause significant health problems in individuals living with the illness (Chong et al., 2016; Hsiao & Van Riper, 2009; Robson & Gray, 2007). For example, schizophrenia causes considerable disability and burden worldwide (Alexander et al., 2016; Hidru, Osman, Lolokote, & Li, 2016). Similarly, bipolar

disorder affects 2-3% of the population, yet living with the disease poses a variety of challenges not only to individuals with the illness but also to their families and society (Granek, Danan, Bersudsky, & Osher, 2016; Tanriverdi & Ekinci, 2012). Impairments caused by SMI generally prevent sufferers from carrying out major life activities independently (Adeosun, 2013; Armstrong et al., 2013; Chang et al., 2016) as a result, informal caregivers often take up the unexpected responsibilities of care (Jeyagurunathan et al., 2017). Studies show that the difficulties and challenges posed by SMI may have unfavourable long-term consequences on the health of caregivers (Tan et al., 2012; Vitaliano, Zhang, & Scanlan, 2003).

Over the last 40 years, the mental health system has observed a shift in the management of people with SMI from institutions to the communities (Baronet, 2003; Zegwaard, Aartsen, Cuijpers, & Grypdonck, 2011) where formal community care structures provide care to individuals with SMI (Harvey et al., 2008; Tan et al., 2012; Thunyadee, Sitthimongkol, Sangon, Chai-Aroon, & Hegadoren, 2015). Advocates of this shift, often referred to as de-institutionalization, have argued that providing mental healthcare services in the communities increases access (Kauye et al., 2011; Pan, Ng, & Young, 2016; Sono, Oshima, & Ito, 2008). While de-institutionalization has shown promising results in HIC, a number of challenges to this approach have been reported in LMIC (Asher et al., 2016; Papastavrou, Charalambous, Tsangari, & Karayiannis, 2010). The challenges may include: inadequate resources, poverty and lack of updated policies (Iseselo & Ambikile, 2017; Shidhaye, Lund, & Chisholm, 2015). In Malawi for instance, a lack of physical and human resources, including inadequate bed capacity in both public and private hospitals, are some of the serious problems faced by the health sector (Kauye et al., 2011; Palmer, 2006).

Unfortunately when these formal community-based structures are not in place, responsibilities of caregiving often fall onto the family and friends (Chang et al., 2016; Zeng, Zhou, & Lin, 2016) who often times remain unpaid for the care they provide (Adeosun, 2013; Chepngeno-Langat, 2014; Pearlin, Mullan, Semple, & Skaff, 1990; Penning & Wu, 2016). Despite the increasing burden caused by SMI, the impact on the caregivers is not fully recognised (Caqueo-Urizar et al., 2014). Informal caregiving is regarded as a distressing responsibility that comes with increased demand that affects the wellbeing of caregivers (Pearlin et al., 1990; Power & Kuyken, 1998; Struening et al., 2001). Available evidence suggests that members responsible for the informal caregiving may eventually get distressed and develop stress related symptoms and depression (Del-Pino-Casado, Frias-Osuna, Palomino-Moral, et al., 2011; Stensletten, Bruvik, Espehaug, & Drageset, 2016; Suresky, Zauszniewski, & Bekhet, 2014). This means that caregivers may face unexpected problems due to the caregiving role.

Several studies both qualitative and quantitative on caregiving burden are well documented in HIC (Jack-Ide, Uys, & Middleton, 2013; Quah, 2014). A systematic review on the burden of schizophrenia, by Chong et al. (2016) shows that more than 80% of studies were conducted in HIC compared to 20% in LMIC. These findings are consistent with available literature which indicate paucity of data on caregiving burden studies in Sub-Saharan Africa (Addo, Agyemang, Tozan, & Nonvignon, 2018; Adeosun, 2013; Adewuya, Owoeye, & Erinfolami, 2011; Chepngeno-Langat, 2014). The majority of studies conducted tend to focus on specific conditions like schizophrenia. However, few studies have focussed on dementia/frailty, depression, intellectual disability and bipolar disorder (Dos Santos et al., 2017; Schofield, Murphy, Herrman, Bloch, & Singh, 1997). Additionally, most studies have dealt with caregivers looking after adult care recipients rather than children and adolescents with SMI (Knock, Kline, Schiffman, Maynard, & Reeves, 2011). Given this gap in the literature, the question remains on whether the type of burden in caring for children and adolescents with SMI is different from caregiving for adult with different forms of SMI (Penning & Wu, 2016).

A search for studies in Malawi investigating caregiving burden in relation to SMI reveals a general lack of literature on the subject as only two studies were conducted. One investigated knowledge of schizophrenia among caregivers and indicated that caregivers who acquired knowledge following family psychoeducation of schizophrenia had an increased level of burden (Sefasi et al., 2008). The other study focused on caregivers of children with intellectual disabilities. This second study found burden in the areas of finance, housing and stigma and that women were more likely to be affected than men (Mwale, Mathanga, Silungwe, Kauye, & Gladstone, 2016). The two studies however, looked at specific informal caregiving of either children or adults with SMI. No study in Malawi has investigated caregiving burden and associated factors of caregivers comparing children and adults in the same study.

The present study intended to expand on the available research in a number of ways. First, the study investigated the burden of caring for both children and adults. Second, it included caregivers that care for individuals with any form of SMI. Finally, it adopted a theory-based approach applicable to research and practice in explaining factors related to caregiving burden. The different theories and selection of the preferred one are discussed in the literature review section. Findings derived from this study are expected to assist in establishing recommendations for improving services for caregivers (Hsiao & Tsai, 2014; Shamsaei, Cheraghi, & Bashirian, 2015).

1.2 Aim & Objectives

The main aim of this study is to investigate the prevalence and associated factors of caregiving burden among caregivers of individuals with SMI at SJOGHS in Mzuzu Northern Malawi. Specific objectives include:

- To determine the prevalence of caregiving burden among caregivers of children and adults with SMI.
- To examine the relationship between socio-demographics, age of care recipient, and diseases related factors and caregiving burden among caregivers of individuals with SMI.

1.3 Thesis outline

The following are the chapters in this thesis: Chapter Two reviews the literature. Chapter Three describes the methodology employed to address the study objectives. Chapter Four presents the study findings, while Chapter Five is the discussion which synthesises the findings in relation to the international literature and concludes with recommendations.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This Chapter reviews literature on the prevalence and associated burden of SMI on a global scale and in LMIC. The Chapter then concentrates on the available literature and service accessibility of people with SMI in these regions. Lastly the Chapter describes in detail the adopted conceptual framework and theories in caregiving studies. Different search methods were applied in identifying relevant literature. Searches were done in PubMed, Google Scholar, and following up references from articles obtained. The broad search for literature used the following key words *(caregiving burden,) and (psychosis, schizophrenia or severe mental illness*). The study only included studies published in English.

2.2 Prevalence and implications of SMI

As earlier reported, 450 million people across the globe suffer from mental disorders (Liu, Lambert, & Lambert, 2007). In addition to CMDs such as anxiety and depression, mental disorders also include SMI such as schizophrenia and related disorders (Jeon et al., 2004). The prevalence and associated burden of SMI is an important issue of growing professional and social interest globally. Therefore, assessing prevalence of SMI is essential. According to Wiersma (2006) the prevalence of SMI in the general population was previously reported to be 0.7%. However, other studies found different prevalence rate and projections of several investigations show that the prevalence of SMI will continue to rise. For instance, a systematic review on the prevalence of schizophrenia drawn from 46 countries found the lifetime prevalence of the disease to be 4%, contesting the frequently cited estimate of 1% (Saha et al., 2005). Similarly, bipolar disorder affects approximately 2-3% of the population (Granek et al., 2016).

Although data indicates that SMI are less prevalent than CMDs in LMIC, living with SMI poses a variety of challenges to families and society. Much evidence has accrued from previous studies indicating that individuals with SMI often experience a combination of physical, emotional and behavioural problems (Tan et al., 2012; Vitaliano et al., 2003). The challenges associated with SMI are likely to become chronic (Robson & Gray, 2007), in the process causing impairment in function that affect the individual's ability to carry out major life activities (Adeosun, 2013; Armstrong et al., 2013; Chang et al., 2016). Therefore, caregivers take up a wide range of long term responsibilities of caring for the affected care recipients in addition to the formal health care services (Bleijlevens et al., 2014; Collins & Swartz, 2011). The prolonged caregiving role may result in caregiving burden of caregivers. This scenario may further contribute to an increase in the number of relapses, disability, and

mortality among care recipients because of lack support from the affected caregivers (Scott et al., 2016). The following, section discusses SMI and service accessibility in LMIC.

2.3 SMI and service accessibility in LMIC

As earlier stated, individuals living with SMI require a range of long term care from informal caregivers in addition to formal health care services (Bleijlevens et al., 2014; Townsend-White, Pham, & Vassos, 2012). Despite causing impairment, and the availability of effective treatment, gaining access to services for SMI remains a challenge (Shidhaye et al., 2015). A growing evidence indicate that strategies of addressing the challenges exist (Friedman-Yakoobian, Mueser, Giuliano, Goff, & Seidman, 2009). One such strategy is the WHO's "Optimal Mix of Services Pyramid framework" that aims to guide LMIC in addressing the mental health treatment gap (Shidhaye et al., 2015). As shown in figure 1 below, the framework has five levels that include "self-care (level 1)"; "informal community care" (level 2); "primary-care mental health services" (level 3); "psychiatric services in general hospitals, and community mental health services" (level 4); and "long stay facilities and specialist psychiatric services" (level 5). However, development of mental health services has been slow in most of LMIC (Saraceno et al., 2007). Several barriers to the development of these services have been reported. These may include lack of budget allocation, lack of mental health personnel and limited knowledge even among health professionals (Chilale, Silungwe, Gondwe, & Masulani-Mwale, 2017; Rugema, Krantz, Mogren, Ntaganira, & Persson, 2015).

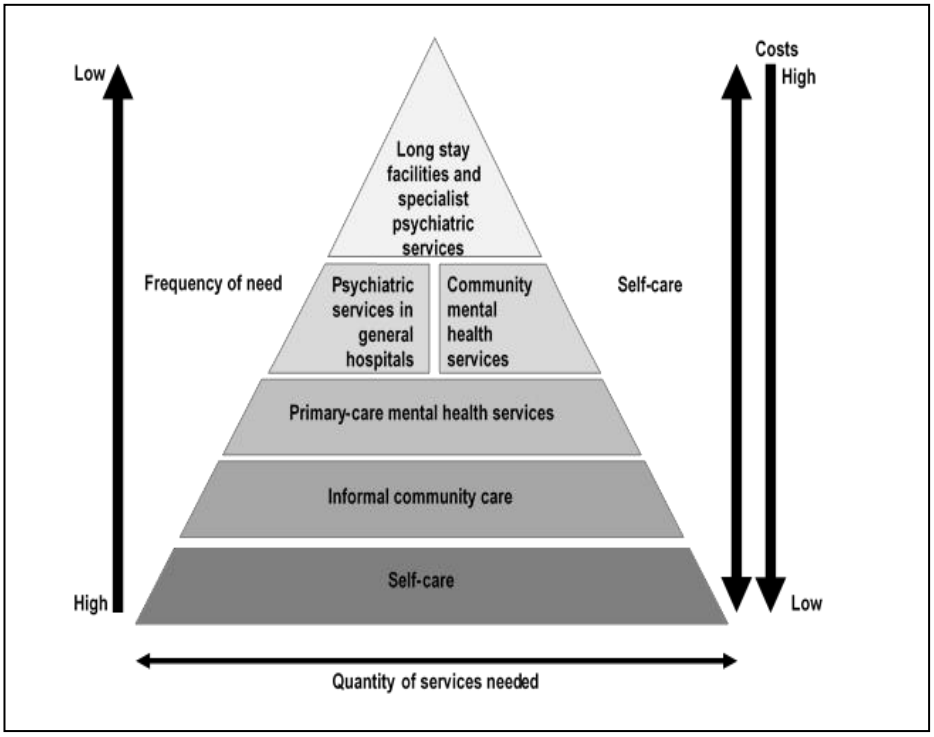

Figure 1: "The optimal mix of services: WHO Pyramid Framework Source": "Organization of Services for Mental Health: Mental Health Policy and Service Guidance Package. Geneva: WHO, 2003"

Unfortunately, in Malawi and in many other LMIC, most mental health services are provided at costly tertiary level hospitals with little to no available services at primary healthcare level or the community (Kauye et al., 2011; Kauye, Udedi, & Mafuta, 2015).

2.4 Mental health care in Malawi

Although there is scarcity of mental health survey data for Malawi, the burden of disease attributed to MNS disorders is significant (Bowie, 2006; Malawi National Mental Health Policy, 2001). Disability in Malawi is commonly caused by MNS disorders that rank fourth after HIV/AIDS, malaria and cataract (Crabb et al., 2012). According to a draft of the Malawi National Mental Health Policy (2001) estimates of disease burden are based on studies done in LMIC with similar health profile as Malawi. The seriousness of the burden caused by non-communicable diseases (NCDs), including mental health, led the Malawi government to commit itself to fighting the problem through the inclusion of the NCDs into the Health Sector Strategic Planning for 2011–2016 (Kachimanga et al., 2017). However, despite having available treatment for MNS disorders, Chilale et al. (2017) argue that in Malawi, help-seeking behaviours for MNS disorders remains a challenge. There are a number of factors that may delay help seeking behaviours as discussed below.

In Malawi, there is lack of trained mental health providers (Kutcher et al., 2017). Most of the services regarding mental health are provided by non-specialised health care workers (Udedi, Swartz, Stewart, & Kauye, 2013). The country has only four psychiatrists serving in public service and none in private service. The number of specialists is not adequate to cover the population of approximately 18 million people. The situation is complicated as mental health service provision is often only provided at tertiary level care with very limited community mental health services (Udedi et al., 2013). This makes for poor and limited access to mental health services (Kauye et al., 2011).

A growing advocacy for countries to promote integration of mental health services into primary health care, has become an important way of managing people with SMI (Bleijlevens et al., 2014; Dambi, Tapera, Chiwaridzo, Tadyanemhandu, & Nhunzvi, 2017). This system has been reported to improve outcomes (WHO, 2008). In Malawi, most of the primary health care services for mental health disorders remain limited as mental health services have not yet been fully integrated into primary healthcare services (Udedi, 2014; Udedi et al., 2013). This state of affairs creates a situation where the majority of people remain untreated (Chilale et al., 2017). This is evident with the study by Chilale, Banda, Muyawa, and Kaminga (2014) in northern Malawi that found an average duration of untreated psychosis to be 52 weeks, a longer period than reported in HIC. This poor access to services usually result into increased levels of disease burden (Udedi et al., 2013). Additionally, traditional culture plays a significant role as a barrier as many people in Malawi live in communities that hold strong beliefs that mental illness is caused by spiritual possession that resolves on its own or through help from traditional healers (Abbo et al., 2008; Chilale et al., 2017; Crabb et al., 2012). This usually delays help seeking behaviours as noted earlier.

In summary, effectiveness of community intervention programs and a number of ways to achieve this have been suggested (Asher et al., 2016). Interventions may include: allocation of more resources in all countries, formal training of informal caregivers on the caregiving role and timely measures to overcome barriers in informal caregiving (Greenberger & Litwin, 2002). To attain all these suggested measures, an intensive and comprehensive management systems within the communities where all stakeholders are involved (Kageyama, Yokoyama, Nakamura, & Kobayashi, 2015) must be developed and advocated for in a country like Malawi.

2.5 Caregiving and caregiving burden

According to Collins and Swartz (2011), a caregiver is defined as a friend or relative who provides help to an individual who is not able to care for himself/herself as a result of an injury, illness, disability or other chronic conditions. Wang, Xiao, He, Ullah, and De Bellis

(2014) reports two types of caregiving, namely, formal and informal. Previous studies have reported that formal caregiving involves professionals such as clinicians, nurses, and sometimes individuals who are paid as part of their work (Brown & Brown, 2014; Dambi, Mandizvidza, Chiwaridzo, Nhunzvi, & Tadyanemhandu, 2017; Sanuade & Boatemaa, 2015). Informal caregiving on the other hand, involves family members, friends and acquaintances who do not get paid for the care they render to their care recipients (Akpan-Idiok & Anarado, 2014; Penning & Wu, 2016; Sharma, Chakrabarti, & Grover, 2016). Most studies use the term “family caregiver” which is interchangeably used with the term “informal caregiver” in some literature in order to reflect that the services rendered to an individual with SMI are not paid for (Bastawrous, Gignac, Kapral, & Cameron, 2015; Collins & Swartz, 2011). It is this criterion of not paying for the care rendered that has given rise to an agreement of adopting the term family caregiver (Bastawrous et al., 2015; Sanuade & Boatemaa, 2015).

In recent years, there has been an increased interest in informal caregiving studies worldwide. The concept is seen to emerge as a public health concern that will affect every individual (Hatfield, 1997; Lunsky, Tint, Robinson, Gordeyko, & Ouellette-Kuntz, 2014). Previous studies have shown that caregivers take up caregiving responsibilities without any preparation for the task (Chien, Chan, & Morrissey, 2007; Ghannam, Hamdan-Mansour, & Al Abeiat, 2017) yet the process of providing care is a distressing responsibility (Struening et al., 2001). Moreover, most caregivers usually have little or no resources for the unexpected demand of their role (Dos Santos et al., 2017) and the demand may be so huge that caregivers may themselves develop psychopathology (Adewuya et al., 2011). Informal caregivers may present with grief, demoralization, anxiety, depression or some form of physical disorder (Del-Pino-Casado, Frias-Osuna, Palomino-Moral, et al., 2011; Stensletten et al., 2016; Suresky et al., 2014). However, despite the need for public officials to acknowledge and address the needs of informal caregivers, most of them remain unnoticed by the formal health care systems as the majority provide caregiving without seeking help (Chepngeno-Langat, 2014). This situation may lead to recurrent relapses of care recipients due to lack of care from the affected caregivers (Alexander et al., 2016; Beentjes, Goossens, & Poslawsky, 2012).

A growing consensus among researchers indicates that caregiving activities can be appraised negatively or positively (Baronet, 2003; Ghannam et al., 2017). Looking at the negative appraisal, this is where caregivers experience an increased level of stress that builds slowly due to the caregiving activities (Alexander et al., 2016; Thunyadee et al., 2015; Zegwaard et al., 2011). Studies have conceptualized caregiving burden into two areas based on objective and subjective dimensions (Bastawrous, 2013). The objective dimension refers to consequences resulting from the day to day problems that caregivers encounter directly

when providing care (Bastawrous, 2013; Bauer et al., 2011; Bauer, Koepke, Sterzinger, & Spiessl, 2012); for example, the time spent in caregiving, the financial loss incurred due to the caregiving process and activities of daily living (ADL) (Grover et al., 2014). Subjective burden refers to the mental reaction expressed by caregivers (Graessel, Berth, Lichte, & Grau, 2014; Perlick et al., 2016). These are emotional problems and attitude such as distress, depression, anxiety, irritation, or feelings of exhaustion due to stressors associated to the caregiving role (Pearlin et al., 1990).

On the other hand, informal caregiving can be appraised positively. In some societies caregiving is regarded as rewarding phenomenon that brings satisfaction and other positive aspects (Kim & Chung, 2016; (Chang et al., 2016; Penning & Wu, 2016; Rodriguez-Perez, Abreu-Sanchez, Rojas-Ocana, & Del-Pino-Casado, 2017). For example in Ghana, caring for someone with SMI is taken as one of the highest honours and favour (Sanuade & Boatemaa, 2015). Similarly in Malawi caregiving is highly regarded as a human value of caring for someone who is in need of help (Sefasi et al., 2008). For example, a study that investigated caregiving correlates and its positive aspects among caregivers of people with schizophrenia in North India, found multiple correlation between Quality of life (QOL) and positive aspects of caregiving, suggesting that caregiving process may improve QOL among caregivers (Kate, Grover, Kulhara, & Nehra, 2013). This can be achieved through spending time together, being sensitive to an individual with a SMI or disability (Kim & Chung, 2016). Informal caregiving can also improve a sense of inner strength among caregivers and can bring about positive relationships among family members, in the end creating a sense of being needed (Gupta, Isherwood, Jones, & Van Impe, 2015).

Globally, the concept of caregiving has been provided differently from region to region. For example, in LMIC the concept remains part of the informal health and welfare care system (Aldersey, Turnbull, & Turnbull, 2016). This may be due to several factors that may include lack of social systems that link caregivers with the health system (Kim & Chung, 2016). This supports the earlier argument that most informal caregivers often remain unseen within the health systems of many LMIC as compared to those in HIC (Chepngeno-Langat, 2014; Collins & Swartz, 2011). The differences in the health and welfare systems of HIC and LMIC brings variations in the savings associated with informal caregiving activities for the two regions. In LMIC the cost to the health systems associated with informal caregiving is seen to be large, however, in HIC, this has resulted in significant savings (Corry, While, Neenan, & Smith, 2015). In LMIC the lack of formal community based care and support for caregiving means that the family caregivers shoulder much of the cost. While savings in HIC, could be that caregivers are less likely to need health care services as they are often supported and

trained. In United States for instance, the system contributes to an estimates $375 billion towards healthcare savings (Collins & Swartz, 2011) while in United Kingdom and Republic of Ireland, an estimate of £119 billion and €5 billion was realised respectively (Corry et al., 2015). The reason of the high cost in LMIC could be that most caregivers end up using their own little resources towards the caregiving activities, yet do not often get the necessary support or formal training on the caregiving process(Chepngeno-Langat, 2014).

Tan et al. (2012) and Yazici et al. (2016) suggest that for an informal caregiver to provide appropriate support to their relative or friend, they need to have willingness, coping skills, knowledge, mental and physical energy, economic power and eagerness for such a high demanding task. Equally, caring for children with complex neurological conditions also requires high demand of effort, time and patience (Hoefman et al., 2014). However, many informal caregivers do not have the required knowledge or resources and normally have less power to cope with the challenges of caregiving role (Daire & Mitcham-Smith, 2006; Jack-Ide et al., 2013; Manor-Binyamini, 2010). Furthermore, most caregivers are not prepared for the conflicting demands and responsibilities of the caregiving situation (Alzahrani, Fallata, Alabdulwahab, Alsafi, & Bashawri, 2017; Baldwin, Kleeman, Stevens, & Rasin, 1989). Instead they assume the unexpected informal role that requires their full-time attention unlike in formal occupation, which allows for formal training and annual leave (Dambi, Mandizvidza, et al., 2017; Quah, 2014). Some caregivers may perceive the condition of the person with SMI to be more important than their own behaviour, symptoms or level of functioning and feel responsible to provide assistance, in the process neglecting their own health (Ducharme, Lebel, Lachance, & Trudeau, 2006; Jorge & Chaves, 2012). As a result they could experience many negative outcomes of the caregiving process (Shamsaei et al., 2015). Several studies have measured caregiving burden (Fried, Bradley, O'Leary, & Byers, 2005). The following section outlines the concept of measuring caregiving burden.

2.6 Measuring caregiving burden

Since caregiving burden became a significant aspect in family caregiving studies, there has been several attempts to measure the concept (Chou, Chu, Tseng, & Lu, 2003). However, measuring the concept, has been associated with challenges. While the caregiving burden was previously regarded as a unidimensional construct focusing on monetary cost in families (Parham et al., 2016), other studies have conceptualized the term to include the importance of subjectivity of caregivers (Carrà, Cazzullo, & Clerici, 2012; Chou et al., 2003). Therefore, there is a need to consider several factors when measuring caregiving burden. The factors may include: differences in culture, political, social, religion, ethical and other personal factors (Chou et al., 2003; Wang et al., 2014). For instance, some important contextual

caregiver factors, such as culture, may not be captured when quantitative design is used to measure the burden (Bastawrous, 2013). Additionally, most definitions are derived from theories or models from studies conducted in HIC (Chou et al., 2003).

It is against this background that Bastawrous (2013) suggested the use of a clear theoretical framework across studies in order to provide comparative evidence. According to Caqueo-Urizar et al. (2014) the use of theories is to attain an integral conceptualisation of caregiving burden. There are a few theories of caregiving that have been used in researching caregiving burden. Bastawrous (2013) suggest that two useful theories of caregiving burden are the 'Role theory' and 'Stress theory'. Role theory considers the gendered nature of caregiving and how the caregiver role interacts with other roles of the person giving care (Bastawrous, 2013). While this is an important aspect of caregiving, understanding the caregiving role and its interaction with other roles seems better researched using qualitative methods. The Stress theory as exemplified in the Pearlin Stress Process Model (Bastawrous, 2013; Caqueo-Urizar et al., 2014; Pearlin, Menaghan, Lieberman, & Mullan, 1981) provides a useful theoretical framework for quantitative research in caregiving burden.

In addition to the use of theories, there has been a number of caregiving burden measures that have been developed and used in both HIC and LMIC (Fried et al., 2005; Schreiner, Morimoto, Arai, & Zarit, 2006). Some common measurements include the use of measurement instruments such as: "the Zarit's Burden Interview (ZBI) (Ankri, Andrieu, Beaufils, Grand, & Henrard, 2005b; Gort et al., 2007), Montgomery's Burden Scale (Chou et al., 2003), Vitaliano's Screen for Caregiver Burden (Chou et al., 2003), Novak's Caregiver Burden Inventory (Chou et al., 2003), Kosberg Cairl's Cost of Care Index (Chou et al., 2003) and the Involvement Evaluation Questionnaire (IEQ)" (Sefasi et al., 2008). However, Harvey et al. (2008) argue that many instruments lack reliability, validity and sensitivity as such, it has been suggested for caregiving burden researchers to always take caution when selecting a measuring instrument. This study adopted the ZBI based on its psychometric properties and wide use in caregiving studies. The instrument is discussed in detail in the methodology section.

2.7 Prevalence of careging burden

Although there is a growing interest in informal caregiving globally, data in LMIC is scarce (Adeosun, 2013). Most of the results on the prevalence of caregiving burden are from HIC (Lambert et al., 2017). The outcomes of the reports on studies conducted in LMIC show variation in the prevalence. As earlier reported, the differences may be due to variations in methodologies, cultural aspects, behaviour and social characteristics of individuals with SMI

(Chou et al., 2003; Souza et al., 2017). For example, moderate to severe level of burden was found in Nigeria where a ZBI mean score of 42.85 was found in a study that assessed correlation of psychopathology of SMI and burden (Adewuya et al., 2011). Similarly, moderate levels of care burden were found in a study that assessed caregiving burden of people with mental illness using the IEQ in Saudi Arabia, where a mean score of 38.4 was obtained (Alzahrani et al., 2017).

On the global level, the situation is similar as the outcome of caregiving burden differs across different countries. For instance, a study that examined demographic and social determinants of caregiver burden among 115 caregivers of people with schizophrenia in a Caribbean country reported a ZBI mean score of 30, suggesting that many had mild to moderate burden (Alexander et al., 2016). Some studies found lower caregiving of burden levels. For instance, a low ZBI mean score was found in a study of 74 caregivers that looked at factors associated with caregiver burden in Australia (Campbell et al., 2008). Findings of this Australian study, show a ZBI mean score of 18.02. In Brazil, a ZBI mean score of 27.66 was found in a study that investigated factors associated with burden of care for people with SMI (Souza et al., 2017). Further comparison with other studies show some variation in the outcome. Other studies report high levels of caregiving burden as measured on the ZBI. A study done in Turkey investigating the relationship between caregiving burden and the effect of self-efficacy among 62 caregivers of people with schizophrenia found a ZBI mean score of 68.64, indicating severe burden (Durmaz & Okanlı, 2014; Souza et al., 2017). Similarly high levels of burden (ZBI mean score of 51.73) were found in Iran in a study investigating the prevalence of caregiving burden among caregivers of people with schizophrenia (Shamsaei et al., 2015).

In addition to the results of burden of caring for adults, findings on the burden of caregivers for child and adolescents have also been reported. For example, in Nigeria, a study that assessed predictors of caring for children and adolescents in a psychiatric hospital, found a moderate to severe level of burden among caregivers (Dada, Okewole, Ogun, & Bello-Mojeed, 2011). Similar, results were found in a comparative study of 300 caregivers of children with developmental disorders (n=300) and 100 caregivers of children with no disorders in Israel (n=100) (Manor-Binyamini, 2010). Caregivers of children with developmental disorders had a higher caregiver burden than those with no disorders.

As earlier indicated, not many studies on caregiving burden have been conducted in Malawi. One study looked at the association between schizophrenia knowledge and caregiver burden (Sefasi et al., 2008). The authors conducted a baseline assessment of caregiving

burden with the Involvement Evaluation Questionnaire (IEQ) while providing psychoeducation on schizophrenia to the caregivers. Thereafter, another follow-up assessment was done and results of the IEQ show a mean score of 26.7 among caregivers who received the psychoeducation, suggesting that caregivers who acquired knowledge about schizophrenia were associated with an increased caregiving burden. However, authors argue that, the results do not imply a causal effect between knowledge and caregiver burden but this may be attributed to some cultural aspects that may mediate the association. The other study was a qualitative study that explored caring for children with intellectual disabilities (Mwale et al., 2016). The authors of this study found burden in the areas of finance, housing and stigma and that women caregivers were more likely to be affected. A recent quantitative study reveals high level of distress among parents of children with intellectual disabilities (Masulani-Mwale, Kauye, Gladstone, & Mathanga, 2018). The next section discusses a conceptual framework and theories for understanding caregiving. It also describes the model that this study adopted including how different factors within the model play in relation to caregiving burden.

2.8 Conceptual framework for caregiving research

The Stress Process Model provided the theoretical framework for this study. The model has been widely used in many caregiving studies and its use has been found to be relevant in addressing strategies and concepts in caregiving. In addition to this, it has also been reported to be culturally sensitive to various caregiver population (Del-Pino-Casado, Frias-Osuna, & Palomino-Moral, 2011). According to Pearlin et al. (1981) the Stress Process Model was built on Lazarus and Folkman's (1987) Transaction Conceptual Model that suggests that there is a dynamic interaction between an individual and the environment that causes stress (Goh, Sawang, & Oei, 2012). The theory suggest that, it is the existence of stressors and resources that cause individuals to be affected (Pearlin et al., 1990). Therefore, stress occurs when the interaction exceeds the resources the individual has for coping that then threaten psychological and physical wellness of an individual (Merluzzi, Philip, Vachon, & Heitzmann, 2011).

Stress among caregivers has been examined across different SMI using the Stress Process Model and some differences in responses to stressful conditions among caregivers have been reported. Studies report that despite the strength and resilience that some caregivers may tolerate, the process of caregiving may negatively affect their QOL (Del-Pino-Casado, Frias-Osuna, Palomino-Moral, et al., 2011; Pearlin et al., 1990) that may worsen with the progression of the SMI (Struening et al., 2001).

The study opted for the Stress Process Model for a number of reasons; firstly, the model provides a good understanding on how stress relates to the caregiving process (Lee, Kim, & Kim, 2006). Secondly, the guide that is provided by the model, assists researchers in getting an insight into how the caregiving variables affect each other within the construct. Finally, it further explains and emphasises how individuals are affected by the presence of stressors and resources (Bastawrous, 2013). Figure 1, below depicts aspects of the Stress Process Model.

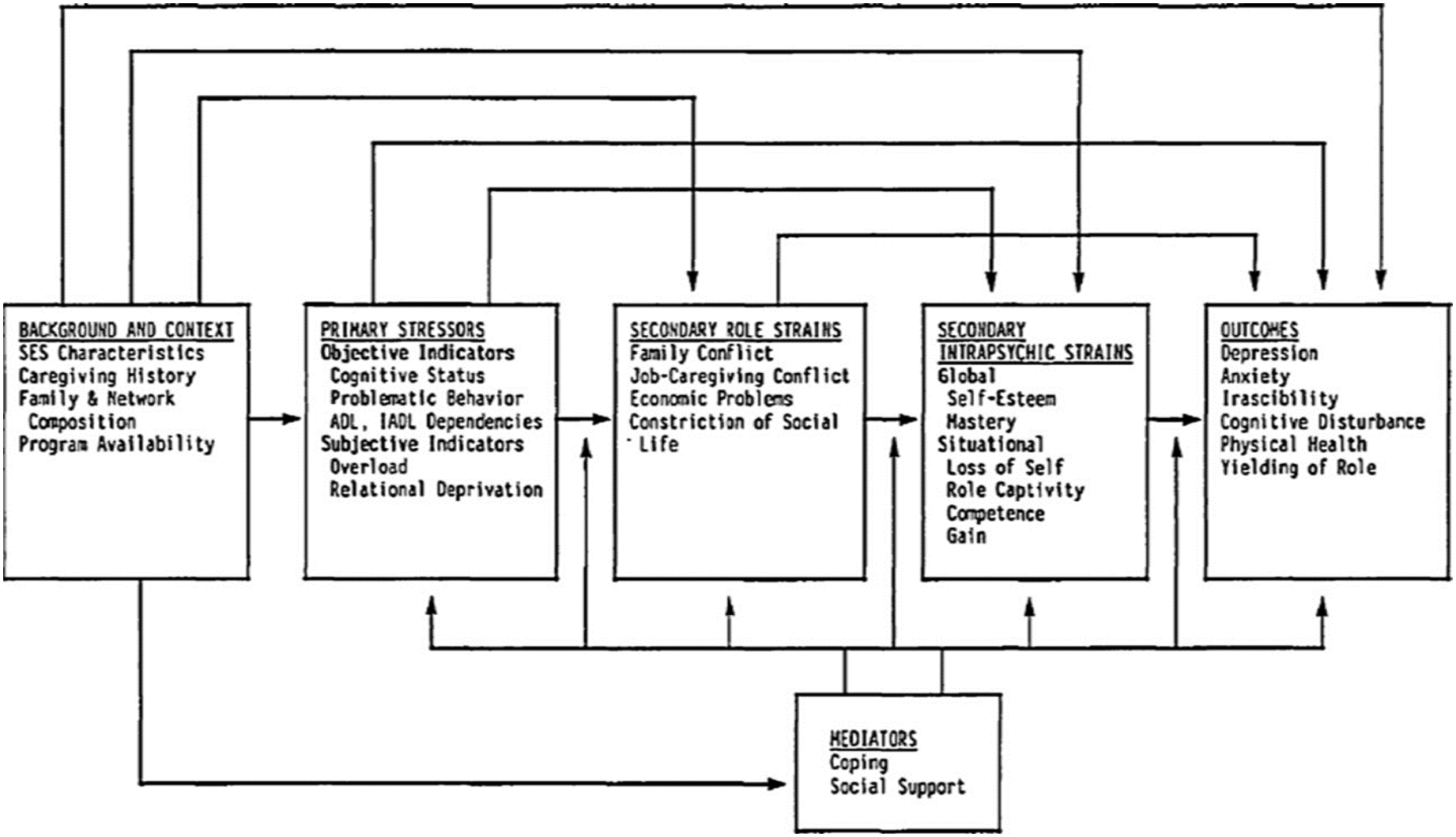

Figure 2: Depicting the Pearlin Stress Process Model that was adopted from Pearlin et al.'s Stress Process Model (1990)

2.9 Description of the Stress Process Model

The stress associated with caregiving predisposes caregivers to experience negative physical, emotional and mental health problems (Lee et al., 2006). Riley-McHugh, Hepburn Brown, and Lindo (2016) state that the model assumes that caring for individuals with SMI at home makes caregivers increasingly susceptible to persistent strain. Pearlin et al. (1990) further describe that stress arises from the interaction of variables. These include: resources, social economic characteristics, and stressors to which caregivers are exposed to (Pearlin et al., 1990; Thunyadee et al., 2015). Below, is a detailed description of the Stress Process Model.

The Stress Process Model categorises factors related to stress into four major domains that explain how variables relate to each other (Papastavrou et al., 2007; Winslow, 1997). These include: the background and context, sources of stress, mediators of stress and manifestation of stress (Kaufman, Kosberg, Leeper, & Tang, 2010; Pearlin et al., 1981). Background comprises characteristics of a caregiver, such as gender, age, ethnicity, educational background, social economic status, occupation and relationship with a care recipient (Del-Pino-Casado, Frias-Osuna, Palomino-Moral, et al., 2011). Context includes aspects of the caregiving situation, such as conditions of care recipient illness, period for caregiving and resources.

Stressors are situations that a caregiver considers problematic (Pearlin et al., 1990; Riley-McHugh et al., 2016). As earlier illustrated, these may be either primary or secondary. Primary stressors can result in secondary stressors that are referred to as secondary role and intrapsychic strains (e.g., family conflict, self-esteem, conflicts, competence or economic problems) that are not within the caregiving situation. Primary stressors may be the effects on the health of caregivers due caregiving process (Campbell et al., 2008; Riley-McHugh et al., 2016). These may be due to changes in financial status, family routines due to the cognitive status or problematic behaviours of care recipients (Riley-McHugh et al., 2016). Additionally, behavioural problems may create a situation where care recipient becomes a risk to themselves or to others. This situation may therefore create some demands for caregivers in meeting the needs of the care recipients (Pearlin et al., 1990). Secondary stressors refer to demands that come due to the illness of care recipients (Pearlin et al., 1990). Pearlin et al. (1981) suggested three indicators that appraise the caregiving strain: decreased household income, excess expenditure related to caregiving activities and the availability of finances for the family survival. Due to increased stress, a caregiver can feel trapped in the caregiving process a situation that is referred to as role captivity (Pearlin et al., 1981).

Mediators are aspects like coping skills and social support (Carretero, Garces, & Rodenas, 2007). Mediators assist caregivers in preventing secondary stressors and may include support from other family members, friends, neighbours, community. Coping skills are different strategies that caregivers apply in dealing with situations that cause stress (Pearlin et al., 1990). Outcomes are the effects of the caregiving process that indicate the wellbeing of caregivers.

Table 1: Definition and examples of stressors and types of caregiving burden

	Definition	**Example**
Stressors	Conditions that cause stress	
Primary	Conditions, experiences and activities that caregivers considers problematic	Cognitive status or problematic behaviors of a care recipient
Secondary	Demands that comes due to SMI of care recipient	Decreased household income, excess expenditure related to caregiving activities
Caregiving Burden	Response to the exposure to life strains and events that occurs overtime as a result of the caregiving experience	
Subjective	Mental reaction expressed by caregivers	Distress, depression, anxiety, irritation, exhaustion
Objective	Consequences resulting from the day to day problems that caregivers encounter when providing care to their care recipients.	Time spent in caregiving, financial loss

By using the Stress Process Model, caregiving burden is regarded as a response to the exposure to life strains and events that occurs overtime as a result of the caregiving experience (Gupta, Pillai , & Levy, 2012; Gupta et al., 2015; Vitaliano, Russo, Young, Teri, & Maiuro, 1991). Akpan-Idiok and Anarado (2014) refers to this as a response to "a multidimensional bio-psychosocial reaction" that emanates from the multiple roles that usually create an imbalance on the personal time, social roles, financial resources, physical and emotional state of caregivers due to the high caregiving demands (Akpan-Idiok & Anarado, 2014; Campbell et al., 2008). For instance, when a family member develops a SMI,

the ability of caregivers to fully participate in their own regular social activities is often thwarted due to the responsibility of providing support to their family member.

The caregiving role within the Stress Process Model is examined holistically through application of a multifaceted approach in which caregiving outcomes are explained by connecting the primary and secondary stressors within a situation in which care is being provided (Zehner Ourada & Walker, 2014). Stress usually comes through hardships that are associated with the chronicity of the illness and other factors related to the environment in which caregivers provide care; for example, providing care to someone with disorganised behaviour and assisting someone with reduced self-care throughout the night instead of resting (Grau, Graessel, & Berth, 2015).

The Pearlin Stress Process model guided the study through the description of the family stress processes as stated above. The stress process model was selected because it has the basic three components of stressors, mediators, and outcomes that are used in stress modelling (Goh et al., 2012). In addition, the model used because of its usefulness in caregiving research that assesses caregiver's perception and response to stress (Pearlin, 2010). In the study, informal caregivers were the subject of analysis and predictor variables included: care recipients and caregivers social demographic characteristics, ADL that caregivers performed, symptom severity and time spent on caregiving, social support as a mediator of stress, and the outcome variable was the caregiving burden (Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007).

As earlier reported, caregiving can be appraised either negatively or positively. A call has been made for future studies on caregiving burden to utilise theories that focus on both positive and negative caregiving experiences (Bastawrous, 2013). This study used a multidimensional measure that has both subjective and objective burden domains. The next section discusses factors associated with caregiving burden.

2.10 Factors associated with caregiving burden

A growing number of studies that previously utilised the Stress Process Model found several factors that are associated with caregiving burden (Bastawrous, 2013; Chiao, Wu, & Hsiao, 2015; Shamsaei et al., 2015; Wang et al., 2007; Zhou et al., 2016). Researchers have measured these factors extensively in order to formulate evidence based services for informal caregivers (Bastawrous, 2013). Although there are differences among countries globally, similar factors have been identified (Urízar, Maldonado, & Castillo, 2009). Some factors are more associated with negative effects while others are associated with positive

aspects (Crowe & Brinkley, 2015; Penning & Wu, 2016). Literature often divides these factors in line with the Stress Process Model. They involve: (i) characteristics of care recipients and caregivers, and (ii) caregiving related factors (Caqueo-Urizar et al., 2014; Liang et al., 2016).

This section will describe these categories of factors in relation to the available literature. It will begin with description of care recipient's related factors, then caregiver's related factors and caregiving related factors.

2.10.1 Care recipient related factors of burden

A number of characteristics of care recipients with SMI have been found to significantly predict caregiving burden (Kim, Chang, Rose, & Kim, 2011). These patient characteristics range from their demographic characteristics, disease related factors and behaviour or psychological factors (Chiao et al., 2015). Some socio-demographic factors of a care recipients that include age, gender, education, religion, employment and ethnicity have been found to correlate with caregiving burden (Chang et al., 2016; Sanuade & Boatemaa, 2015). For example, one study on caregivers of schizophrenic care recipients found greater caregiving burden for older compared to the young caregivers (Alexander et al., 2016).

Another factor associated with caregiving burden is the clinical characteristics of care recipients. These may include the type of SMI, severity of symptoms, and duration of treatment as well as cognitive decline of care recipients due to SMI (Dauphinot et al., 2016; Shamsaei et al., 2015). A study in Japan that investigated factors of caregiving burden related to anorexia nervosa, found severity of the condition predicted the levels of burden and poor health outcomes of caregivers (Ohara et al., 2016). Similarly, caregivers of individuals with decreased level of social functioning due to SMI have been reported to show a significant increase in caregiving burden (Dos Santos et al., 2017). Suresky et al. (2014) report that increased illness severity causes serious disruption of family relationships and financial decline that results in an increased burden on relatives. In one study severity of the disability of a child was associated with poor psychological and physical health outcome of caregivers (Roper, Allred, Mandleco, Freeborn, & Dyches, 2014).

The type of SMI or disability also has a significant impact on caregiving burden. Roper et al. (2014) report that caregivers of children with various disabilities experience different results of stress and burden. For instance, parents of autistic children report significantly higher levels of stress and burden than parents of children with Down's syndrome (DS) (Abbeduto et al., 2004). Similarly, caregivers of typically developing children have less stress and burden than those with autism and other disabilities (Manor-Binyamini, 2010; Olsson & Hwang, 2001). Serious conditions in children, like conduct disorders and cerebral palsy,

cause serious impairments that place a great demand on caregivers resulting in an increased caregiving burden (Dambi, Mandizvidza, et al., 2017; Hendricks, Lansford, Deater-Deckard, & Bornstein, 2014).

Lastly, care recipient factors associated with caregiving burden include behaviour and psychological characteristics (Perlicka et al., 2007). This is supported by a report by Raina et al. (2004) who emphasised the association of disability and behaviour problems with SMI. For instance, caregivers of psychological and problematic behaviour, experience higher caregiver burden than those without these difficulties (Chiao et al., 2015; Mwale et al., 2016).

2.10.2 Caregiver related factors of burden

As described by the Stress Process Model, the caregiver's characteristics play an important role in determining the formation of stress (Kim et al., 2011). These include caregiver's age, gender, place of residence, family composition, level of education, religion, occupation, social support, relationship with the care recipient, and duration the caregiver has been living with a care recipient. The following section discusses caregivers factors associated with caregiving burden.

Caregiver's age has been found to correlate with caregiving burden (Papastavrou et al., 2010). Older caregivers have been found to experience more stress and burden compared to the younger ones (Pinquart & Sorensen, 2007). It has been suggested that older caregivers worry about who will take over from them in the caregiving process in the event of death or being weak for the caregiving role (Fujino & Okamura, 2009).

The gender of a caregiver is another important factor associated with caregiving burden (Thunyadee et al., 2015). Studies have found that women are more likely to take a leading role than men in the caregiving process (Chepngeno-Langat, 2014). Thus women experience more caregiving burden than men (Adeosun, 2013). This is due to different social systems and cultural demands and gender roles that women experience (Yusuf, Nuhu, & Akinbiyi, 2009). Some cultures require women to take a leading role in the caregiving process. This way of doing things is common worldwide (Mwale et al., 2016; Roberto & Jarrott, 2008; Sharma et al., 2016; Slaunwhite, Ronis, Sun, & Peters, 2016; Yusuf et al., 2009). However, few studies have also found inconsistent results in terms of gender (Adewuya et al., 2011; Sharma et al., 2016). A study by Adewuya et al. (2011) found that being male had a significant correlation with increased levels of subjective burden compared to being female. Adewuya et al. (2011) suggest that this could also be because men did not consider caregiving as their expected role and so found this a greater subjective burden. These authors further stress that women's roles are more often seen as caregiving than men's roles.

Being employed has also been found to contribute to the reduction of caregiving burden compared to being unemployed (Sanuade & Boatemaa, 2015). However, findings by Adewuya et al. (2011) indicate that employment is a significant predictor of subjective burden. The authors suggest that the results might be that caregivers divide their time in caring for their care recipients and work, a situation that may predispose them to stress and burden. Another study in Nigeria did not find any association between employment and burden (Yusuf et al., 2009). The differences in findings may suggest the need for further robust controlled studies in providing clear differences in these findings.

One of the factors in the Context domain within the Stress Process Model is the number of people living in a household. Family composition has also been found to influence caregiving burden. Literature indicates that caregivers who come from families that have five or more members are likely to experience less caregiving burden than those with less members (Adeosun, 2013). This may be because large families share caregiving responsibilities among themselves (Sefasi et al., 2008).

Another factor that has been found to determine caregiving burden is the caregiver's level of education (Chiao et al., 2015). In a study that looked at the burden of caregivers of people living with schizophrenia, a significant association was found showing that higher education levels were associated with higher levels of perceived burden (Shamsaei et al., 2015). However, other studies found that higher education level correlated with low burden (Adeosun, 2013; Alexander et al., 2016; Papastavrou et al., 2010). The low burden level with high education can be attributed to the presence of enough resources for the caregivers.

Religion plays an important role in the caregiving process. A study by Sanuade and Boatemaa (2015) looked at caregiver profiles and determinants of burden in Ghana. Findings revealed that believers (Christians in this case) had reduced levels of caregiving burden compared non-believers. May be this is because being part of a church provides social and other support.

According to the Stress Process Model, social support mediates stress. Perceived social support as a determinant of caregiving burden has been studied widely in several studies (Aldersey et al., 2016; Boydell et al., 2014; Pinquart & Sorensen, 2007). For example, differences in levels of burden has been observed among caregivers caring for the elderly in Japan. Lower levels of burden were found among caregivers who received informal social support (Kikuzawa, 2016). Similarly, a qualitative study by Riley-McHugh et al. (2016) that explored coping mechanism and psychological effects among caregivers of people with schizophrenia, found high level of burden for those without social support. Outcomes from previous studies indicate that families that have adequate social support have decreased

levels of psychological effects of caregiving and report less caregiving burden (Hsiao & Tsai, 2014; Hsiao & Van Riper, 2009; Morin & St-Onge, 2015).

Studies have reported that caregivers of children who exhibit less behaviour problems and who receive adequate family support have a better perception of their children's condition and improved psychological health (Chou, Pu, Lee, Lin, & Kroger, 2009; Kuhn & Laird, 2014; Sanuade & Boatemaa, 2015). Although, caregiver stress and burden is reported to be associated with social support, a study by Boydell et al. (2014) found no significant association between social support and burden. These authors attributed this to the availability of general practitioners to whom caregivers confided their feelings about their caregiving role. This process is believed to have enhanced the positive aspects of caregiving without affecting burden.

Factors such as interpersonal relationships within the family circle are also significant predictors of caregiving burden (Hsiao & Tsai, 2014). In families where there is a good relationship between a person with SMI and their caregivers, the levels of caregiving burden are reported to be low (Gupta et al., 2012). On the other hand, families with strained relationships usually experience more caregiving burden (Grover et al., 2014). For example, Crowe and Brinkley (2015) found an increased level of caregiving burden in caregivers with strained relationship with their care recipients. Similarly, a study in Switzerland found caregiving burden in families with strained relationships that later disintegrated as a result of caregiving responsibilities (Rexhaj, Jose, Golay, & Favrod, 2016). The type of relationship has also been found to significantly predict caregiving burden. For example, close relations, like parental caregivers, have been reported to experience higher caregiving burden than other types of informal caregivers that include siblings (Hsiao & Tsai, 2014). Although, interpersonal relationships is considered as an important predictor of caregiving burden, the causal pathway is most likely to be bi-directional as caregiving burden may cause strained relationships and strained relationships can cause caregiving burden.

Previous studies have found an association between the duration of a SMI including the period that caregivers have been providing care and caregiving burden (Chilale et al., 2014; Mwale et al., 2016; Ohara et al., 2016). Families with care recipients with longer duration of illness often experience negative psychological and stressful impact of caregiving and report high caregiving burden (Chiao et al., 2015). This is consistent with findings from Eritrea where the longer duration of caring for someone with schizophrenia, increased caregiving burden (Hidru et al., 2016). In Nigeria Dada et al. (2011) found that diagnosis, duration of an illness and the presence of psychosis predicted caregiving burden in a study in which the authors investigated association of burden with the care recipients and their caregiver's

demographic characteristics. It could be that longer duration means that one learns to cope but in other instances longer duration wears down one's ability to cope. It is always a complex set of factors However, also in Nigeria Adewuya et al. (2011) found no significant association between duration of SMI and subjective burden.

2.10.3 Caregiving related factors

Several tasks associated with caregiving have been reported with different levels of burden. Furthermore, the hours spent caregiving per week predict the amount of distress. Those with higher distress report poor family functioning, communication and satisfaction (Crowe & Brinkley, 2015). Caregivers who have been providing full-time or near full-time care to care recipients are more likely to experience caregiving burden than those who spent less time in the caregiving role.

The other caregiving related factor is the environment in which care is being provided. Several environmental factors have been found to relate with caregiving burden (Asher et al., 2016). One such example is presence of community intervention programs (Asmal, Mall, Emsley, Chiliza, & Swartz, 2014; Baronet, 2003). Developing good intervention programs and mental health policies is an important factor in caregiving (Brady, Kangas, & McGill, 2016; Parker, Mills, & Abbey, 2008). Several studies have observed that these programs are effective in targeting determinants of mental health that alleviate financial, psychosocial and other mental health related burdens for both informal caregivers and care recipients (Asher et al., 2016; Kuhn & Laird, 2014; Lai, 2012; Van Houtven, Voils, & Weinberger, 2011).

For the caregiver to provide effective caregiving, there should be resources. These may include a number of things such as: presence of recreation and vocational centres within the community; presence of community self-help groups, clinics, community emergence response teams and other basic necessities. The presence of adequate resources have been reported to reduce caregiving burden compared with where there are limited or no resources (Riley-McHugh et al., 2016). For example, a study in Chile with caregivers of people with schizophrenia found a significant difference in caregiving burden in two differently resourced contexts. There were low levels of burden among caregivers who lived in a reasonably well-resourced city as compared to those in the northern part of the country where resources were low (Caqueo-Urizar et al., 2011). Similarly, a study in Nigeria found that caregivers living in rural areas, where mental health resources are inadequate, experienced a greater burden than those in urban areas where they do not travel long distances to access help for their relatives (Yusuf et al., 2009).

Understanding the socio-economic status of caregivers remain important as financial costs that caregivers incur when providing care has been reported to predict caregiving burden

(Lai, 2012). Stress may occur in places where people are affected financially. For example, in every society there is an uneven distribution of rewards, opportunities, privileges and responsibilities among people (Bauer et al., 2012). Some stressful situations, such as having a family member or friend with a SMI may trigger some social processes regulated by some economic status of people within that society (Iseselo & Ambikile, 2017).

Given the existing evidence on factors that determine caregiving burden in a number of studies, this study aims to investigate these factors within the Malawi context, compare caregiving burden for children and adults with SMI, and contribute to the global evidence base on caregiving burden.

CHAPTER THREE: METHODOLOGY

3.1 Introduction

This section covers the study design applied to investigate prevalence of caregiving burden and associated factors among caregivers of individuals with SMI at SJOGHS in Mzuzu Northern Malawi. The section also describes the study site, population, inclusion and exclusion criteria, study procedure, measures, sampling technique and sample size, data collection methods, measurement tool that was used, analysis strategy, ethical considerations and study limitations.

3.2 Study design

The study adopted a hospital based cross-sectional study. According to Chou et al. (2003), quantitative designs can inform evidence-based policy because of their ability to reveal statistical significance of certain caregiving burden correlates. In addition, it is relatively simple to apply quantitative caregiver measures in clinical settings to identify at-risk individuals, given that these instruments are short and quick to administer.

3.3 Study setting

The study was conducted at SJOGHS Mzuzu Service. The services offered by the hospital are based on Christian ethos, respect for the human dignity, the needy and promotion of mental health in communities. According to a SJOGHS (2018) draft of the strategic plan, services include: children with all forms of disability and/or special needs and community mental health for adults in Mzuzu and surrounding areas. These services are offered through outpatient and community programs, such as rehabilitation and vocational training for people recovering from mental illnesses, people with disabilities and other special needs; special education and community rehabilitation for children with disabilities and epilepsy; rehabilitation programs for children living in and on the streets of Mzuzu city and self-help group initiatives for poor families, regardless of whether they have someone with mental health related problems or not. The hospital also provides university level training in psychiatric nursing, clinical medicine (psychiatry/mental health), registered nursing (generic) and psychosocial counselling (SJOGHS, 2018). The SJOGHS Mzuzu services, also include psychosocial counselling to people experiencing a variety of issues in their lives. Additionally, the hospital has a drug and alcohol rehabilitation centre for people struggling with addiction issues.

The present study was conducted in two separate departments within the hospital. These are St John of God Centre (SJOGC) and Child Development Centre (CDC). The SJOGC functions as a Drop-in Centre. The services include: clinical assessment and referrals, outreach clinics, mental health information and education, domiciliary care as an alternative

to inpatient care, home visitation follow-up and after care, addiction recovery program, a prison mental health program and training for student nurses and clinical officers (SJOGHS, 2018).

The CDC on the other hand, offers rehabilitation, education and support services to children and adolescents with special needs and various psychiatric conditions such as attention deficit hyperactive disorder, epilepsy, Down's syndrome, intellectual/physical disabilities, cerebral palsy, in order for them to attain their optimal level of functioning while ensuring integration into their community. The centre runs an institute of special education, parent support group, nutrition support and outreach clinics where services are provided to children with epilepsy and/or other disability. Other additional services offered by the department include mental health assessments by qualified Mental Health Clinical Officers, treatment, rehabilitation and education. These two centres (CDC and SJOGC) are within the same yard only 100 metres apart. A combined average of approximately 600-700 patients attend these services monthly.

3.4 Study population

The study population were adult caregivers of care recipients presently receiving outpatient treatment at SJOGC and CDC.

3.5 Sample

Some studies suggest that in a situation where there is no available data for a complete list of caregivers of people with SMI, it is impossible to draw a representative sample (Quah, 2014). This is reported as a common challenge in many research studies on caregiving. The study site did not have available data for informal caregivers and the alternative option was to use a purposive sampling technic which Vogt (2007) suggests is the best method to use when a probability sample is not possible. Therefore, we were unable to ascertain the true prevalence of caregiving burden. For that reason, the power analysis for this study was based on multiple regression. "Power analysis for a multiple regression with 15 predictors was conducted in G*Power to determine a sufficient sample size using an alpha of 0.05, a power of 0.80, and a medium effect size (f2 = 0.15) (Faul et al., 2013). Based on the aforementioned assumptions, the desired sample size" was 139. Therefore, the study aimed to recruit 150 participants to allow for refusals. The following were the inclusion and exclusion criteria:

3.6 Inclusion criteria:

- The usual caregivers who spent some time with the care recipients with SMI for 3 or more days a week
- Caregivers who were not paid for the services
- Those who were 18 years or older
- All caregivers who lived with care recipients for not less than three months
- Those who were willing to provide informed consent
- Caregivers of care recipients who met the criteria for SMI and had been in treatment for more than six months

3.7 The exclusion criteria:

- Caregivers who accompanied care recipients on the day of recruitment but were not the usual caregivers
- Caregivers who came with care recipients in an acute phase even if they met the criteria. The assumption was that caregivers could not concentrate on the interview to provide required information due to concern for the state of their care recipients at that time of an interview
- Caregivers refusing consent or withdrawing from the study

3.8 Participant recruitment

In this study two research assistants were recruited to assist the researcher with data collection. The assistants are qualified health care workers: a Public Health Officer and a Mental Health Clinical Officer.

The researcher conducted a one week training for the two research assistants on the tool, collection and management of data. The assistants were directed by the researcher who is familiar with arrangements and processes at both centres in accessing the files of care recipients. At the study site a file for every care recipient is kept up to date in an outpatient register. Every care recipient is assigned an identification number that appears on their personal health passport book, where all personal medical records are recorded. Other details of the care recipients are also available in a computerised database that includes dates of the first review when they started receiving services, subsequent dates and that of the next appointment, demographic, diagnosis and where they live. The register also contains details of the identified caregiver of each care recipient, including their contact details. This information is used to follow up those who need support care by the community

team from SJOGC and CDC within their respective communities. The team also follows those suspected to have defaulted treatment, including those placed on domiciliary care.

In order to recruit participants for the study, the researcher reviewed the weekly appointments booked for the hospital and identified caregivers to be approached. This meant, potential eligible caregivers' demographic details were accessed. To ensure a representative group was included in the study, an attempt was made to recruit caregivers of different age groups and caring for either children or adults with varying types of SMI like schizophrenia, bipolar disorder, depression, and all forms of developmental disorders, including intellectual disability in children. A daily target list was developed that the research assistants and researcher used to identify potential participants.

3.9 Study procedure

The research assistants approached all potential caregivers at the waiting area who accompanied their care recipients to meet mental health workers for their regular clinical follow-up. The assistants provided the caregivers with information about the study. They also described the study and the consent process through a script for the study (See Appendix D). This ensured that a similar approach was used for all potential participants. Informed consent was obtained from all eligible caregivers. Information pertaining to the study, confidentiality, anonymity of the process and right to withdraw were discussed. The caregivers were informed that their withdrawal would not affect services received by their relative/friend. Caregivers who were unable to read and write were asked for a thumb print following their acceptance to take part in the study.

Initially it was anticipated that there could be some cases where caregivers may want to discuss their participation with the person they cared for, to avoid causing problems among family members and care recipients. Prior arrangement was made for care recipients to wait for the caregiver at the waiting area after their follow up assessment was completed. However, in this study, there were no caregivers who wanted to discuss their participation with the care recipient.

All consenting participants were interviewed in a private room where they were assured of confidentiality so that the assurance would ensure free expression. The care recipients were asked to either stay in the room with a caregiver or wait in the waiting area. But for the care recipients who felt that they could not wait, they were allowed to leave for their homes once it was deemed safe for them to do so alone. Following completion of the interview, participants were provided with a voucher to buy soap amounting to K500 (just under 1 US$) for their time. This was done at the end of interview to make sure that participants did not view this as a coercion to take part in the study.

3.10 Measures and measuring instruments

Data were collected largely from the primary caregivers while accompanying their care recipients during the routine monthly reviews at the Hospital. Data were collected using two instruments that were completed by the research assistants: The first tool was developed by the researcher and it contained information on demographic details of care recipients and caregivers. In addition, the tool included some clinical characteristics of care recipients such diagnosis, duration of treatment and symptom severity that were obtained from care recipient's case files before an interview with their caregivers (See Appendix A). The second instrument was the ZBI as the measure of caregiving burden.

In this study, measures of caregiving burden were based on the domains and factors identified on the Stress Process Model (Pearlin et al., 1990). However, this study did not consider including all factors that the Model describes. The study examined the following factors: caregivers gender (male, female), caregivers age (in years), caregivers marital status, place of residence, family composition, caregivers education level, caregivers occupation, relationships between caregivers and care recipients, duration of care that an individual with SMI required care, care recipients age, diagnosis of care recipients, duration of treatment, and symptom severity. These characteristics provide an insight on people's socio-demographic status (Pearlin et al., 1990).

However, social support was not measured using a standardised self-report scale in this study. The measurement was based on the common practice in Malawi. In addition to the social demographic characteristics of care recipients and caregivers, social support was measured as a mediating factor of caregiving burden (Amendola, Oliveira, & Alvarenga, 2011; Rosell-Murphy et al., 2014). However, social support was not measured using a standardised self-report scale in this study. The measurement was based on the common practice in Malawi. The people who are perceived to have social support are those who receive any kind of help from others towards their caregiving role. The help may be in form of psychological, physical, monetary and material support. While those without social support do not receive any kind of help from anyone. In view of this, social support was divided into two: those with support and those without support. It is acknowledged that the use of a non-structured tool to measure social support is a limitation in this study.

3.10.1 Zarit Burden Interview (ZBI)

The ZBI is a structured questionnaire that captures caregiver background characteristics that are key to caregiving. The tool has been reviewed, validated and extensively referenced in many caregiving burden studies (Higginson & Gao, 2008). Evidence shows that it is a transcultural measurement that has been widely used in LMIC including: Nigeria, Ghana and Tanzania (which is a neighbour of Malawi) (Paddick et al., 2015; Prince et al., 2012; Uwakwe et al., 2009). It also has good test–retest reliability and high internal consistency (Gort et al., 2007). It measures various caregiver factors (Yusuf et al., 2009). Furthermore, it examines the effects of both stress and burden and can differentiate between objective and subjective burden among caregivers. Most researchers use the 22 item version that has a 5-point Likert scale that ranges from 0-4 (Ankri et al., 2005b). Caregivers are asked to indicate if they had various thoughts or feelings about their caregiving experience. On the scale 0 is 'never' while 4 is 'nearly always'. The total burden is obtained by adding the scores for all items with a range of 0 to 88. The scores that range from 0-20 indicate no burden, 21-40 indicate mild to moderate burden, 41-60 moderate to severe burden and 61-88 severe burden (Olawale, 2014).

In addition to reporting on the subdomains of the ZBI (described earlier), this study further dichotomised the scale into two levels. The main reason for this was to investigate the factors associated with caregiving burden through a logistic regression analysis. Previous studies that used the ZBI suggested using the cut-off point of 26. This cut off point has been found valid in identifying caregivers in need of assessment for possible intervention (Gater et al., 2015). Caregivers who scored a total of less than 26 on the scale were considered to have no caregiving burden while those who scored a total of 26 and more were regarded as having caregiving burden.

3.10.2 Rating symptom severity of care recipients

In this study, ratings of symptom severity of care recipients were based on information from caregivers and clinical records. Symptom severity were classified into four categories: 1) those in remission; 2) those with mild symptoms; 3) moderate symptoms; and 4) severe symptoms. This is not a formal classification but one devised for this study based on experience. Care recipients in remission were those with a stable mental state and were able to function in all areas (psychological, social and occupational) for more than three months prior to the date of assessment. Those with mild SMI had presence of some symptoms with little difficulties in the level of functioning, those with moderate SMI had symptoms and some difficulties in performing activities in one of the three domains

(psychological, social and occupational functioning). While those with very severe symptoms had impairment in all the three spheres.

The final classification was established on clinical judgment by the assessor (research assistant) based on the caregiver rating and information from clinical records. The main reason for not collecting data directly from care recipients using a structured objective methods is because it was practically complicated and not feasible given that the sample size was large. Moreover, doing so would require two sets of interviews that would involve both caregivers and care recipients that would also require seeking consent from the care recipients in addition to their caregivers. In addition, administering a scale would require an adequate amount of time for the assessment before making a final rating. Because of this, it was not possible to adopt the use of a structured tool on care recipients in this study. A training on how to rate symptom severity were also done with research assistants by the researcher. The assistants used data from case files of care recipients to check presence of symptoms and the level of function as a basis to categorise the level of symptom severity. However, the use of an un-validated classification system and not directly measuring severity of symptoms of care recipients is seen as a limitation but given the focus on caregivers and the fact that all care recipients had de facto severe mental illness, this limitation is deemed acceptable for purposes of this study. Most of the care recipient's information were taken from the files. However, additional information was obtained during an interview with the caregiver. Research assistants gathered information on care recipients socio-demographic details including, care recipients diagnoses, duration of the illness, duration of the treatment, and period of time a care recipient had lived with a caregiver.

A number of socio-demographic characteristics about the caregivers themselves were collected. This included: age, gender, education level, employment, source of income, ethnicity, family composition, number of care recipients with SMI the caregiver is looking after, relationship with a care recipient and duration the caregiver had lived with the care recipient.

The questionnaire was translated into local languages of Tumbuka and then translated back into English language and reviewed in order to harmonise the two processes to ensure an accurate translation.

3.11 Data analysis

The study used IBM-SPSS version 25 to capture and analyse the data. Demographic and burden of caregiving were explored using descriptive statistics.

The study used non-parametric tests such as a chi-squared on all categorical measurements to test associations between variables and parametric tests such as t test on all continuous variables. The multiple regression analysis used a forced entry method. The unadjusted and adjusted associations between socio-demographic factors of the caregiver and person living with SMI and caregiving burden were analysed using logistic regression. There were two reasons why a linear multiple regression was not conducted. First, the ZBI was not normally distributed, despite attempting a number of ways to do this. Second, if an intervention is going to be developed, it will be developed for those who meet a particular cut off of 26 (the at risk group). In this study independent variables were the socio-demographic details of caregivers and care recipients including care recipients' diagnosis, family composition and duration of treatment, while the dependent variable was the caregiving burden. The cut of point on the ZBI was at 25-26 meaning those with no burden had scores that ranged from 0 to 25 and all who scored 26 and above were regarded as having caregiving burden. In this study, findings were presented using tables.

3.12 Ethical considerations.

The researcher made sure that all procedures were appropriately followed. The proposal was submitted to the Human Research Ethics Committee (HREC) in South Africa of UCT and the National Health Sciences Research Committee (NHSRC) in Malawi. Authorization to conduct a study at SJOGHS in Malawi, was sought from the Country Director of Services. This was confirmed by letters of permission from the ethics committees (see appendix G). Written as well as verbal consents were sought from caregivers. Subjects were at liberty to participate or not and were told that their refusal to take part would not affect the usual care of their care recipients. Research assistants provided participants with participants information sheet (PIS) that explained the study in detail while assuring them of confidentiality. Effort were made to keep the participants as short a time as possible. Interview with participants lasted for approximately 45 minutes to an hour. Participants in this study were given a voucher amounting to K500 to thank them for their time taken to respond to research questions and all colleagues working within SJOGC and CDC were made aware of the research study and procedures involved.

CHAPTER FOUR: STUDY RESULTS

4.1 Introduction

This Chapter presents findings of the study. Results are based on the study objectives and are presented in tables and narrative form under the following headlines: socio-demographic profiles of both care recipients and caregivers, and the unadjusted and adjusted associations between socio-demographic characteristics and caregiving burden.

4.2 Socio-demographic profile of participants

This section describes socio-demographic characteristics of the informal caregivers and care recipients as shown in Table 2 and Table 3 respectively. The study contacted 150 caregivers who met the inclusion criteria and 139 were enrolled. There were no missing data and this represented a 100% response rate. The ages of caregivers ranged from 18 to 80 years old with a mean age of 43.1 years. A majority were female (55.5%) with a higher proportion living in urban areas of Mzuzu City (76.6%). Most participants were married (62.6%) and were from families composed of five or more people per household (65.5%). However, the majority of caregivers who indicated that they were married were male (72.6%). With regard to the level of education, there was a higher proportion of those who never completed high school (66.9%). Similarly, caregivers who indicated that they never completed high school, the majority were female (68.8%). All but one participant is practicing Christianity (99.3%). Two thirds were employed and employment in this study meant that a caregiver was doing something for remuneration, such as business, farming or formal employment (65.5%) and two thirds (66.9%) received no social support for their caregiving activities. Under half were the biological parents to caregiving recipients (41.0%) with the rest (59.0%) being brothers, sisters, uncles and other relatives. Most had lived with care recipients for more than one year (97.1%).

The socio-demographic factors that significantly differed between men and women were caregivers' age, marital status, place of residence, caregiver employment status, relationship between caregivers and care recipients ($p<0.05$) as shown on Table 2.

Table 2: Socio-demographic profile of caregivers by gender

Caregivers characteristics	Total (N=139) N (%)	Male (N=62) N (%)	Female (N=77 N (%)	p-value
Age (m, sd)	43.1 (14.3)	46.8 (13.98)	40.1 (13.92)	0.01
Marital Status				0.03
Single	52 (37.4)	17 (27.4)	35 (45.5)	
Married	87 (62.6)	45 (72.6)	42 (54.5)	
Place of residence				0.02
Urban	95 (68.3)	36 (58.1)	59 (76.6)	
Rural	44 (31.7)	26 (41.9)	18 (23.4)	
Family composition				0.39
<5	48 (34.5)	19 (30.6)	29 (37.7)	
>5	91 (65.5)	43 (69.4	48 (62.3)	
Caregivers education level				0.59
No high school	93 (66.9)	40 (64.5)	53 (68.8)	
High school or more	46 (33.1)	22 (35.5)	24 (31.2)	
Religion				0.26
Christians	138 (99.3)	61 (98.4)	77 (100)	
Muslim and others	1 (0.7)	1 (1.6)	0 (0.0)	
Caregivers occupation				0.01
Unemployed	48 (34.5)	14 (22.6)	34 (44.2)	
Employed	91 (65.5)	48 (77.4)	43 (55.8)	
Social support				0.20
No social support	93 (66.9)	45 (72.6)	48 (62.3)	
Social support given	46 (33.1)	17 (27.4)	29 (37.7)	
Relationship to the care recipient				<0.001
Parents	57 (41.0)	14 (22.6)	43 (55.8)	
Others	82 (59.0)	48 (77.4)	34 (44.2)	
Duration of caregiving in years				0.18
(m, sd)	3.0 (0.22)	3.0 (0.23)	3.0 (0.21)	

Of the caregiver recipients (see Table 3), just over half were male (53.2%) and the rest were female. The ages ranged from one to 70 years with a mean age of 30 years. The majority were adult care recipients (74.8%) with only a quarter being children and adolescents (n=35, 25.2%). Slightly half had a diagnosis of schizophrenia and related disorders (55.4%), followed by bipolar disorder (24.5%) and serious mental health illnesses (20.1%). The

majority had received their treatment for a period of more than one year (71.9%) with most of them presenting with some impairments in their level of functioning (75.5%).

On care recipients' socio-demographic factors, only care recipients' age showed significant difference between gender ($p<0.05$) as shown on Table 3.

Table 3: Socio-demographic profile of care recipients

Demographic characteristics	**Total (N=139)**
	N (%)
Age (m, sd)	30.0 (16.53)
Diagnosis	
Schizophrenia and related disorders	77 (55.4)
Bipolar Disorder	34 (24.5)
Serious childhood mental illnesses	28 (20.1)
Duration of treatment	
<One year	39 (28.1)
>One year and above	100 (71.9)
Symptom severity	
Full remission	34 (24.5)
Presence of any impairment	105 (75.5)

4.3 Prevalence of caregiving

The study found a mean caregiving burden score of 31.5 (sd=±16.7). On the four ZBI caregiving burden levels, the general pattern as shown in Table 4 shows that 29% of caregivers had no caregiving burden, a high proportion 42% had experienced mild to moderate caregiving burden, 22% had moderate to severe burden and only 7% had severe caregiving burden.

Table 4: Prevalence of Caregiving

Variable		**Total (N=139) (N= (%)**
Total Caregiving burden **(**m, sd)		31.5 (16.7)
ZBI levels of burden		
None or little burden	(0–21)	40 (28.8)
Mild to moderate	(21–40)	59 (42.4)
Moderate to severe	(41-60)	31 (22.3)
Severe burden	(61-88)	9 (6.5)

4.4 Unadjusted associations between socio-demographic characteristics of caregivers, caregiver recipients and caregiving burden

The unadjusted model for this study included factors considered important in predicting caregiving burden. These were: gender of caregivers, caregivers' age, marital status, place of residence, family composition, education level, caregiver occupation, social support, relationship to the caregiver, age of care recipients, gender of care recipients and duration of treatment. The unadjusted associations between these factors and caregiving that resulted in a significant association included: 1) caregivers' age; 2) caregiver education level; 3) social support; 4) care recipients age; and 5) care recipients gender. The next section report on each factor in detail.

4.4.1 Caregivers' age

As the age of caregivers increased, the odds of experiencing caregiving burden increased by 3 %. In other words, older caregivers were more likely to experience caregiving burden than younger caregivers (OR=1.03, 95% CI 1.00-1.06). There was statistical difference between younger and older caregivers.

4.4.2 Caregivers' education level

The caregivers' education level was dichotomised during analysis. These were (i) never completed high school and (ii) completed high school. There was a statistically significant difference between educational levels of caregivers. Participants who completed high school, were 71% less likely to experience caregiving burden than those who never completed high school (OR=0.29, 95% CI 0.14-0.62).

4.4.3 Social support

Similarly, social support was found to significantly associate with caregiving burden. The study categorised social support into two: those who had no social support and those who received social support for their caregiving activities. Participants who had social support were 71 % less likely to develop caregiving burden than those without social support (OR=0.29, 95% CI 0.14-0.62).

4.4.4 Care recipients' age

The age of care recipients was categorised into two: (i) less than 18 years and (ii) 18 years and above. A unit increase in the age of care recipients, decreased the likelihood for caregiving burden of caregivers by 3%. In other words, caregivers of older care recipients were less likely to experience caregiving burden than those of younger care recipients (OR=0.26, 95% CI 0.11-0.64).

In addition to gender of caregiver all the variables that were significant in the unadjusted model were incorporated in the final model.

Table 5: Unadjusted and adjusted associations between socio-demographic characteristics and caregiving burden

Variable	Caregiving Burden		Unadjusted OR (95% CI)	Adjusted OR (95% CI)
	No	**Yes**		
	N (%)	**N (%)**		
	63 (45.3)	76 (54.7)		
Caregivers' gender				
Female	36 (57.1%)	41 (53.9)	1.00	1.00
Male	27 (42.9%)	35 (46.1)	1.14 (0.58-2.23)	1.20 (0.52-2.76)
Caregivers' age (mean, SD)	39.54 (14.38)	46.03 (13.62)	1.03 (1.01-1.06)*	1.03 (1.00-1.06)*
Marital Status				
Single	24 (38.1)	28 (36.8)	1.00	
Married	39 (61.9)	48 (63.2)	1.06 (0.53-2.10)	
Place of residence				
Urban	42 (66.7)	53 (69.7)	1.00	
Rural	21 (33.3)	23 (30.3)	0.87 (0.42-1.78)	
Family composition				
<5	24 (38.1)	24 (31.6)	1.00	
>5	39 (61.9)	52 (68.4)	1.33 (0.66-2.69)	
Caregivers education				
No high school	33 (52.4)	60 (78.9)	1.00	1.00
Completed high school	30 (47.6)	16 (21.1)	0.29 (0.14-0.62)*	0.48 (0.20-1.16)
Caregivers occupation				
Unemployed	20 (31.7)	28 (36.8)	1.00	
Employed	43 (68.3)	48 (63.2)	0.80 (0.39-1.62)	
Social support				
No social support	33 (52.4)	60 (78.9)	1.00	1.00
Social support provided	30 (47.6)	16 (21.1)	0.29 (0.14-0.62)*	0.27 (0.11-0.65)*
Relationship to the care recipient				
Parents	23 (36.5)	34 (44.7)	1.00	
Others	40 (63.5)	42 (55.3)	0.71 (0.36-1.41)	
Care recipients Age				
=<17 years	8 (12.7)	27 (35.5)	1.00	1.00
=>18years	55 (87.3)	49 (64.5)	0.26 (0.11-0.64)*	0.17 (0.06-0.50)*

Care recipient Gender				
Male	26 (41.3)	48 (63.2)	1.00	1.00
Female	37 (58.7)	28 (36.8)	0.41 (0.21-0.81)*	0.48 (0.22-1.04)
Duration of treatment				
< One year	17 (27.0)	22 (28.9)	1.00	
=> One year	46 (73.0)	54 (71.1)	0.91 (0.43-1.91)	
Symptom severity				
Full remission	27 (42.9%)	7 (9.2%)	1	
Presence of impairment (mild, moderate or severe)	36 (57.1%)	69 (90.8%)	7.4 (2.9-18.6)	6.3 (2.0-20.0)

4.5 Adjusted associations between socio-demographic characteristics and caregiving burden.

Table 5 also shows results for the adjusted associations of participant's characteristics with caregiving burden. When caregivers' gender, caregivers' age, level of education, social support, care recipients' age and care recipients gender were included in the multivariate logistic regression model, only caregivers' age, social support and care recipients' age remained significant. Being older was still significantly associated with mild to moderate caregiving burden (OR=1.03, 95% CI 1.00-1.06). After adjusting for other variables, caregivers who received social support for their caregiving activities from others were still significantly less likely to experience caregiving burden (OR=0.27, 95% CI 0.11-1.65). In other words, participants will no social support were 73% more likely to develop caregiving burden than those with social support. As regards to age, the final model showed that caregivers who were caring for adults care recipients were 64.5% less likely to develop caregiving burden than those who looked after children or adolescents with SMI (OR=0.17, 95% CI 0.06-0.50).

CHAPTER FIVE: DISCUSSION

5.1 Introduction

This Chapter discusses findings presented in Chapter Four. It starts with a discussion on the main findings of the study and compares these to the available literature. The implications of the study findings are then described. The Chapter will conclusion with discussion on study limitations and overall conclusion.

5.2 Study main findings

This study intended to expand on the available research on caregiving burden in Malawi. The overall aim was to investigate the prevalence and associated factors of caregiving burden among caregivers of individuals with any form of SMI at SJOGHS in Mzuzu Northern Malawi. The specific objectives for this study were (i) to determine the prevalence of caregiving burden among caregivers, and (ii) to examine the relationship between socio-demographic factors and caregiving burden.

5.3 Prevalence of caregiving burden among caregivers

In the present study the overall mean score of caregiving burden measured on the ZBI was 31.5 which lies well within the mild-moderate range (Ankri, Andrieu, Beaufils, Grand, & Henrard, 2005a). When compared with results of previous studies internationally, although relatively consistent with a few studies, this prevalence of caregiving burden is relatively low. For instance, a study investigating the caregiver burden among 115 caregivers of schizophrenia in the Caribbean also reported that most caregivers experienced mild to moderate caregiving burden with a mean score of 30 on the ZBI (Alexander et al., 2016). In Brazil a slightly lower ZBI mean score than the present study was also found (27.66). However, other studies found higher mean scores for caregiving burden than the present study. For example, in Turkey a mean score of 68.64 was found (Duggleby et al., 2016). Similarly more severe levels of caregiving burden were found in studies conducted in Nigeria and Iran with reported mean scores of 42.85 and 51.73 respectively (Adewuya et al., 2011; Shamsaei et al., 2015). An overview of these different studies are presented in Table 6.

Table 6: Summary of distribution of caregiving ZBI mean scores across countries

Paper	Country	Type of SMI	Number of participants	Sampling Methods	Score on ZBI (m, sd)
Adewuya et al., 2011	Nigeria	Anxiety/Depression and Schizophrenia	338	Simple Random Sampling	42.85 (19.31)
Alexander et al., 2016)	Caribbean	Schizophrenia	115	Convenience Sampling	30.0 (14.7)
Alzahrani et al., 2017	Israel	Depression, anxiety, psychosis, brain syndrome, substance abuse, personality disorders	377	Random Sampling	38.4 (17.5)
Campbell et al., 2008	Brazil	Dementia	74	Convenience Sampling	18.02 (9.94)
Durmaz & Okanlı, 2014	Turkey	Schizophrenia	62	No Sampling Method performed	68.64 (18.60)
Sefasi et al., 2008	Malawi	Schizophrenia	90	Random Sampling	26.7 (22.6)
Souza et al., 2017	Turkey	Anxiety, Schizophrenia, Bipolar Affective Disorder, Depression and Mental retardation	281	Non Probability Sampling	27.66 (14.53)
Banda, Schneider & Sorsdahl	Malawi	Schizophrenia and related disorders, Bipolar disorders, Depression and Serious Childhood Illnesses	139	Purposive	31.5 (±16.7)

The results for this study are comparable with previous studies done in Malawi. Although there were some differences in the methodologies across the studies, all confirm the presence of caregiving burden in Malawi. For example, one study investigated association between schizophrenia knowledge and caregiver burden in Malawi (Sefasi et al., 2008). Results for the study found an Involvement Evaluation Questionnaire mean score of 26.7 suggesting low burden among caregivers who acquired knowledge about schizophrenia following psychoeducation. The authors suggest that this low level of caregiver burden could be due to under-reporting in a culture that sees caring for one's family as a basic component of everyday life. Two other studies on caregivers of children with intellectual disabilities did not report the results using mean scores, as one study was a qualitative study. However, the two studies show that caregivers experienced caregiving burden in the area of social, finance and psychological aspects (Masulani-Mwale et al., 2018; Mwale et al., 2016). These results add to the knowledge gap regarding informal caregiving burden in Malawi.

The mild to moderate level of caregiving burden found in this study may be due to several factors. Firstly, participants were all receiving treatment from the two outpatients departments. Therefore, the participants were more likely to be on treatment and relatively stable, resulting in potentially lower levels of caregiving burden. Second, this study was conducted at SJOGHS, a facility that offers different community intervention programs including psychoeducation and psychosocial services to care recipients and caregiver which may have reduced caregiving burden. The use of family psychoeducation as an adjunct intervention to the existing health services has proven useful (Wei, McGrath, Hayden, & Kutcher, 2015). When families acquire adequate information regarding the caregiving role, the ability to carry the caregiving role is enhanced (Savundranayagam, Montgomery, Kosloski, & Little, 2011). This reduces the stress levels that may result in caregiving burden. Third, the Hospital also offers vocational training programs such as carpentry, brick laying and horticulture to care recipients recovering from SMI. Adult care recipients may have been involved in vocational activities, thus creating space for caregivers to have free time to perform other important activities. This conclusion is supported by several studies that reported reduced levels of caregiving burden in areas where there are such programs (Morin & St-Onge, 2015).

However, the assumption of having some community welfare groups in reducing caregiving burden still remains a challenge in Malawi given that it is only SJOGHS that has some established community centres where caregivers meet to discuss issues related to mental health. In addition, these established centres are centralised in the urban area of Mzuzu City. Caregivers coming from rural areas most likely do not receive adequate knowledge of caregiving as compared to their counterparts in the urban areas. Studies have shown that caregiving burden is lower where mental health services have integrated family engagement models that empower and support families with early intervention and recovery approaches for people with SMI (Brady et al., 2016; Chovil, 2009). Therefore the lower caregiving burden levels found in this study may have been reduced due to the presence of such programs (Lucksted, McFarlane, Downing, Dixon, & Adams, 2012). An important follow up would be to investigate caregiving burden among caregivers who are unable to access the services at SJOGHS. The following section explains factors associated with caregiving burden.

5.4 Factors associated with caregiving

In this study, a number of factors were found to be associated with caregiving burden. This confirms the Stress Process Model that explains the dynamic interaction between variables that cause stress (Goh et al., 2012). In the adjusted model only caregivers' age, social support and care recipients' age remained significant.

First, caregiver's age as one of the background and context domain factors in the Stress Process Model has been found to have a strong association with physical strain reported by caregivers (Pinquart & Sorensen, 2007). The findings of this study indicate that older caregivers were more likely to experience caregiving burden than younger caregivers. The likely explanation for this could be related to the social economic factors that older people face. Older people are a vulnerable group who often require care from younger people (Adeosun, 2013). The reason being that older people are often frail with deteriorating health status affecting their ability to perform some important activities (Hosseinpoor, Bergen, & Chatterji, 2013). In addition, many older people are at the age when they would like to rest and leave the responsibilities of care to the younger generation (Fujino & Okamura, 2009). The caregiving role is therefore a burden for older caregivers (Struening et al., 2001). Additionally, the lack of resources faced by these elderly caregivers increases the likelihood of stress as they worry about who will take over from them in the event of death (Adeosun, 2013; Fujino & Okamura, 2009). Younger people may leave the responsibility of care to the elderly, as they regard older people as suitable role models because of their experience in the caregiving process (Chien et al., 2007). Older caregivers may become more burdened than younger caregivers due to the prolonged years of caregiving (Caqueo-Urizar et al., 2011).

Second, social support remains a significant predictor of caregiving burden (Bastawrous et al., 2015; Chien et al., 2007). In families where there are social networks significant improvement in the welfare of caregivers have been reported (Adeosun, 2013; Chien et al., 2007; Kaufman et al., 2010). The explanation for this could be attributed to the shared responsibilities of the caregiving role among different members of the household. For example, social support reduced caregiving burden for carers of people with anorexia nervosa in Japan (Stensletten et al., 2016), and having access to better resources reduced caregiving for carers of intellectually disabled children in China (Cantwell, Muldoon, & Gallagher, 2015; Chiu, Yang, Wong, Li, & Li, 2013). Based on the Stress Process Model, findings of this study confirm social support to be a significant mediator of stress in the caregiving process. Examples, of social support may be in form of psychological, physical, monetary and material support. The result for this study is consistent with findings of other previous studies in which caregivers with social support, experienced lower level of burden compared to those without social support (Kauye et al., 2011)..

Third, the care recipient's age was associated with caregiving in the present study. Caregivers who were looking after adult care recipients were less likely to experience high caregiving burden than those caring for children or adolescents. This finding is inconsistent with other studies that suggest that caring for an adult is more burdensome than caring for

someone young (Pinquart & Sorensen, 2007). However, adult care recipients may have the ability to perform some activities independently as compared to children and adolescents who may need more consistent caregiving throughout the day (Fried et al., 2005). The constant care that children and adolescents require reduces the time available to the caregiver to perform other important duties for the family (Chong et al., 2016). Adult care recipients may be trained to work and live independently. In doing so they may give some room for the caregivers to perform other important activities. Additionally, the high concentration and attention often given to children and adolescents care recipients may take away the care of other children including other family members receive from the caregivers. This may cause strain and tension among family members (Riley-McHugh et al., 2016). The situation may also create some social and economic suffering for the family (Addo et al., 2018; Chong et al., 2016).

In addition to this, the study dealt mainly with care recipients who were coming for their monthly assessment and repeat of their medication and who had a generally stable mental status. Caregivers of adults in the acute and admission unit may report different levels of caregiving burden. The stable state may also be attributed to the medication that older care recipients were taking. The other assumption could be that the SMI of adult care recipients were treatable unlike the lifespan neuropsychiatric disorders of children and adolescents care recipients (Fried et al., 2005; Manor-Binyamini, 2010). For instance, children with developmental disorders usually have impaired cognitive and motor functions that result in constant dependence on their families for activities of daily life (Fried et al., 2005; Manor-Binyamini, 2010). Children and adolescents with SMI also manifest with characteristic symptoms that require a higher demand for care than those without disabilities (Nota, Chikwanha, January, & Dangarembizi, 2015; Wiener, Vohra, Sambamoorthi, & Madhavan, 2016). In Korea, for instance almost 70% of children with intellectual disability were reported to depend on family members even after they grew into adulthood (Kim & Chung, 2016). This means that children and adolescents are usually in a prolonged phase of high dependence compared to the adult care recipients (Sanuade & Boatemaa, 2015).

5.5 Implication of study findings

Even though the caregiving burden found in this study was low compared to previous studies, findings demonstrate that caregiving burden is prevalent among caregivers in Northern Malawi and suggestions to effectively manage the burden have been made. One such way is to have a better understanding of the concept of caregiving burden. This is done through the use of theories which determine the study objectives and procedures (Bastawrous, 2013). This current study provided a theoretical framework that guided the explanation of factors related to caregiving burden. Therefore, the methodology of this study may lay a foundation for future caregiving studies in Malawi and beyond.

The factors found to affect caregiver burden may help researchers and mental health providers come up with strategies on how to manage caregiving burden. For example, this study found that older caregivers were more likely to experience caregiving burden than younger caregivers (Alexander et al., 2016). It is therefore important to consider formulation of policies that assist in establishing community programs that deals with the welfare of the elderly people (Pan et al., 2016; Pinquart & Sorensen, 2007). This may lead to the reduction of caregiving burden among the elderly population. The results may also assist in empowering the youth in taking an active role in the caregiving process.

The study confirms that social support is an important predictor of caregiving burden (Aldersey et al., 2016; Boydell et al., 2014). The study found that caregivers with social support were less likely to experience caregiving burden than those without, making it important to enhance the concept of social support in communities (Kageyama et al., 2015). Therefore, the study may act as a reminder in informing the general public about the need to provide social support in times of need (Chilale et al., 2017; Chirongoma, Chengetanai, & Tadyanemhandu, 2017).

The other important predictor is caring for children and adolescents with SMI. Children and adolescents are a group of people who require constant support from caregivers (Mwale et al., 2016). As discussed in the literature review section, most LMIC such as Malawi face many challenges in managing people with SMI. This treatment gap is often harmful to children and adolescents (Hoefman et al., 2014) and hinders their future wellbeing. The results of this study also confirm that caring for children and adolescents has more severe implications than caring for an adult care recipient (Dada et al., 2011). Therefore, developing effective community programs that emphasise the integration of primary health care for children and adolescents are important.

While this study found three factors (caregivers' age, social support and care recipients' age) to be significant after adjusting for other variables, it is still important to consider other factors

described in the literature, given that the study had its limitations that may have hindered the identification of other relevant factors.

5.6 Study limitations

The findings of this study should be considered in relation to its limitations. Firstly, this study sampled participants from caregivers attending one psychiatric facility in Malawi and did not include caregivers who were caring for people living with SMI but not receiving treatment. Additionally, the study also did not include caregivers of individuals with acute SMI in the inpatients unit as well as those seeking treatment from other outreach clinics under SJOGS and other facilities. This limited the generalization of the findings and may have resulted in the lower than anticipated burden of caregiving. Secondly, this study did not use tools validated for the Malawian context to measure caregiving and associated factors. Thirdly, the ZBI was initially designed as a self-rating scale (Alexander et al., 2016), but many of the caregivers in the present study never completed high school, and as such the interviews were administered by the research assistants to avoid problems of literacy levels. The study considers this as a limitation given that when participants have low literacy levels, it is often assumed that self-administered tools communicate information less clearly than the use of assisted administered interview. However, the administered interview, may miss important information from participants. There was not enough time to observe the relationship between variables and caregiving burden given that the study was cross sectional. Caregiving burden may need an adequate amount of time to observe the possible causal relationship. The other limitation is that the study used an informal method in place of structured objective methods to assess symptom severity and social support.

5.7 Conclusion

The results of this study confirm the presence of various caregiving factors that are associated with caregiving burden, including caregiver's age, social support and care recipient's age. However, there still remains challenges when conceptualising and measuring caregiving burden. This may be due to factors such as culture differences and variation in methodologies. In order to reduce the challenges, the use of theories has been suggested. The present study used the stress Process Model that assisted in conceptualising caregiving burden. Furthermore, the hardships and negative aspects that are associated with the caregiving process necessitates the need for early detection and intervention services. In addition, Flisher et al. (2007) suggest the formation and implementation of national or international policies that may assist in improving the situation of caregivers. Further studies are needed to confirm these findings and to develop interventions targeted at providing practical support for caregivers in Malawi.

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APPENDICES

Appendix A: Research questionnaire-socio-demographic details

Section A: Demographic data

Code of a respondent……

Primary diagnosis of the care recipient…….....

Other diagnosis of the care recipient……...

Gender of the care recipient 1. Male 2. Female

Date of birth of care recipient Day…….Month…….Year…….Age……...

Date of birth of a caregiver Day…….Month……..Year……Age……

Location 1. Urban 2. Rural 3. Other

Religion 1. Christian 2.Muslim 3. Other

Family composition……..

Availability of social Support 1. No 2. Yes

Relationship care recipient/caregiver 1. Friend 2.Son 3. Daughter

4. Father 5. Mother 6. Cousin

7. Grandmother 8. Grandfather

9. Neighbour 10. Other

Marital status of a caregiver 1.Single 2.Married 3.Separated

4. Divorce 5. Widowed 6.Never

7. Married

Education history of a caregiver 1.Never been to School 2.Primary Level

3. Junior Secondary School

4. Completed Secondary School

5. Tertiary School 6.Other

Employment history of a caregiver 1. Formal employment

2. Unemployed

3. Self-employed

4. Small scale business

5. Large scale business

6. Small scale farming

7. Others

Physical/Mental Health problem of a caregiver……..

Duration the caregiver has been living with a care recipient 1. Three-five months

2. Six-eleven months

3. Oneyear-23 months

4. Two and above years

Duration of treatment the care recipient has been receiving 1.Six-11 months

2. One year-23 months

3. Two years and above

Appendix B. The Zarit Burden Interview (ZBI-English version)

Instructions: I am going to be asking you about problems or difficulties you may have had in relation with the mental health/physical problem of your loved one and I were writing down while we are proceeding with the interview.

Questions	Score
1. "Do you feel that your relative asks for more help than he/she needs?"	0 1 2 3 4
2. "Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?"	0 1 2 3 4
3. "Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?"	0 1 2 3 4
4. "Do you feel embarrassed over your relative's behaviour?"	0 1 2 3 4
5. "Do you feel angry when you are around your relative?"	0 1 2 3 4
6. "Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?"	0 1 2 3 4
7. "Are you afraid what the future holds for your relative?"	0 1 2 3 4
8. "Do you feel your relative is dependent on you?"	0 1 2 3 4
9. "Do you feel strained when you are around your relative?"	0 1 2 3 4
10. "Do you feel your health has suffered because of your involvement with your relative?"	0 1 2 3 4
11. "Do you feel that you don't have as much privacy as you would like because of your relative?"	0 1 2 3 4
12. "Do you feel that your social life has suffered because you are caring for your relative?"	0 1 2 3 4
13. "Do you feel uncomfortable about having friends over because of your relative?"	0 1 2 3 4
14. "Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?"	0 1 2 3 4
15. "Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?"	0 1 2 3 4

16. "Do you feel that you were unable to take care of your relative much longer?"	0 1 2 3 4
17. "Do you feel you have lost control of your life since your relative's illness?"	0 1 2 3 4
18. "Do you wish you could leave the care of your relative to someone else?"	0 1 2 3 4
19. "Do you feel uncertain about what to do about your relative?"	0 1 2 3 4
20. "Do you feel you should be doing more for your relative?"	0 1 2 3 4
21. "Do you feel you could do a better job in caring for your relative?"	0 1 2 3 4
22. "Overall, how burdened do you feel in caring for your relative?"	0 1 2 3 4

Interpretation of score:

0 - 21 little or no burden

21 - 40 mild to moderate burden

41 - 60 moderate to severe burden

61 - 88 severe burden

Appendix C: The Zarit Burden Interview (Tumbuka version)

Ndondomeko: Nimufumbeninge zakukhwaska masuzgo agho mungabanabo kukhwaskana na umoyo uwemi wa mkaghanoghano na mthupi wa wakutemweka winu ndipo ndibenge nkhulemba apo ndimufumbeninge

Questions	**Score**
1. Kasi mukughanaghana kuti m'bali winu wakupempha wovwinri mwakujumpha umo wakwenera?	0 1 2 3 4
2. Kasi mukughanaghana kuti chifukwa cha nyengo iyo mukukhala na m'mbali winu, mulije nyengo ya vinthu vinu?	0 1 2 3 4
3. Kasi mukufyenyekezgeka pakati pakupwelerera m'mbali winu na kukwaniska vya kukhumbikwa vinyake vya pa banja na kunvhito	0 1 2 3 4
4. Kasi mukuona kulengeskeka na nkharo ya m'mbali winu	0 1 2 3 4
5. Kasi mukuba na mkwiyo pala muli pafupi na m'mbali winu	0 1 2 3 4
6. Kasi mukughanaghana kuti m'mbali winu wakutimbanizga wene-na-wa banja linu panyake banyinu	0 1 2 3 4
7. Kasi mukuba na mantha pala mukughaghana za nthazi la m'mbali winu?	0 1 2 3 4
8. Kasi mukughanaghana kuti m'mbali winu wakukhalira imwe (wangakhala yayi kwambula imwe?	0 1 2 3 4
9. Kasi mukughanaghana kuti mukusoba mtende pala muli pafupi na m'mbali winu	0 1 2 3 4
10. Kasi mukughanaghana kuti thanzi la moyo winu lakhwaskika chifukwa cha m'mbali winu	0 1 2 3 4
11. Kasi mukughanaghana kuti kusungulika chisisi kwinu kukuchepa chifukwa cha m'mbali winu?	0 1 2 3 4
12. Kasi mughanaghana kuti umoyo winu watimbanizgika chifukwa cha kupwererera m'mbali winu?	0 1 2 3 4
13. Kasi mukuba bambula mtende kuchema banyinu chifukwa cha m'mbali winu	0 1 2 3 4
14. Kasi mukughanaghana kuti m'mbali winu wakukhumba kuti	0 1 2 3 4

mumupwererenge nge kuti ndimwe pera awo wangapokako wovwiri?	
15. Kasi mukughanaghana kuti mulije ndalama zakukwana kuti mupwererere m'mbali winu pachanya pa vyakusoweka vinu	
16. Kasi mukughanaghana kuti mukwanisenge yayi kulutilira kupwererera m'mbali winu?	0 1 2 3 4
17. Kasi mukughanaghana kuti umoyo winu watayika/watimbanikizgika kufumira apo m'mbali winu wakaluwalira?	0 1 2 3 4
18. Kasi mukughanaghana ngeti mungalekera munyake nchito yakupwererera m'bali winu?	0 1 2 3 4
19. Kasi muna chikaiko chili chose apo icho mungachita na m'mbali winu?	0 1 2 3 4
20. Kasi mukughanaghana kuti musazgirepo kapwererero ka m'mbali winu?	0 1 2 3 4
21. ???	0 1 2 3 4
22. Mchisanisani mukughanaghana kuti mwapyoka wuli na nchito yakupwererera m'mbali winu?	0 1 2 3 4

Appendix D: Information and consent forms (English version)

This informed consent form is for the caregivers of individuals with SMI who are attending SJOGC and CDC.

Principal Investigator: Richard Banda,

SJOGHS Mzuzu Malawi.

Email: richardbanda45@gmail.com. Mobile +265 999 1970 45

Supervisors: Prof Katherine Sorsdahl: Department of Psychiatry & Mental Health, UCT. Email: Katherine.Sorsdahl@uct.ac.za. Mobile phone: +27 820 554 676

Prof Marguerite Schneider: Department of Psychiatry & Mental Health, UCT. Email: Marguerite.Schneider@uct.ac.za. Cell phone: +27 73 253 5080

Sponsor: African Mental Health Research Initiative (AMARI)

Project Title: *Prevalence and associated factors of caregiving burden among caregivers of individuals with severe mental illness: A Hospital based study in Mzuzu Malawi.*

Introduction: We are asking if you can agree to take participate in a research study**.** The study focuses on caregivers who are looking after individuals, either children or adults, with any form of serious mental health problems who have been living with the patient for a period of not less than three months and are not paid for the help they are giving. Considering that your loved one is receiving services at St John of God for the stated period, you are eligible to participate in this study, hence your invitation to take part. You may wish to talk to anyone involved in this study whom you feel comfortable with and you can take some time to reflect whether to be involved or not. Feel free to ask on anything that you do not understand at any point during the course of the interview.

Purpose of the Study: It is well known that serious mental illnesses causes serious problems in communities and that the impact caused by these diseases can seriously damage the society as a whole. The current situation in Malawi particularly in Mzuzu is that, when someone suffers from a serious mental illness, much attention is usually given to him/her and less focus is put on people who care for them, as a result people caring for others suffer in silence, a situation that can bring about poor results on both the patient and the people caring for them. Because of this, the purpose of this study is to investigate and establish the problems faced by people who are caring for others with serious mental health problems. The study also is aiming at finding out some factors that are associated with these

problems. Already, other factors have been found in other studies somewhere that show that there is a relationship between the problems that people caring for others face and the mental health problem of the one they are caring for, so we would like to determine if the situation is similar in Malawi. Some of these factors include: Seriousness of the illness of a loved one, number of hours one spends caring for the patient, the kind of support one receives from others when caring for their care recipients and many other factors. The results of this study will help in coming up with plans that are based on evidence in order to help caregivers in the early identification and treatment of their problems.

What to expect in the study: This study will involve a face to face interview where you were asked to answer some questions regarding your relationship with the care recipient receiving care and problems that the mental health condition of your loved one has brought or how it has affected your psychological, social and other aspects of your life. This study will involve two qualified health workers but one of them will interview you in a private room after your loved one has been interviewed and received care. In the event that you are found to have a problem physically or mentally, proper arrangements were made to refer you to an appropriate place where you will receive medical/mental health help.

Voluntary Participation: The decision of you taking part in this study is entirely voluntary. It were upon your choice to participate or not and when you choose not to consent, the services of your loved one will continue and nothing were affected in anyway.

Harm: benefit ratio: The study will not involve any invasive procedures and all measures to avoid causing harm of any sort were taken care of and participants should feel free to express any emotional, psychological problem that the study may impose on them and that appropriate steps were taken before one leaves the room. This study will bring several benefits not only to your loved one but also to you in the event that you are also found with a problem. This will assist in improving the outcome of both your loved one mental health and your own health through identification and treatment of the problem.

Privacy and Confidentiality: In this study only the researcher and assistants will handle and access data in a professional way. All information in the form of hard copies were kept under key and lock and all soft copies were in scripted with a password known to the researcher and research, supervisors and assistants only. The study will only obtain details of a caregiver and the care recipient that are relevant to the study and only codes and not names were used.

Reimbursement for Participation: At the end of an interview you were given a K500 voucher as a token to buy washing soap as an appreciation for your participation and time.

For any question, enquiry or concern about the study contact the Principal Investigator on the address and contacts provided above. In Malawi you can as well contact the National Health Research Ethics Committee of Malawi, Secretariat on (+265) 0888 344 443; (+265) 01 726 418; or Faculty of Health Sciences, Human Research Ethics Committee, UCT, Telephone: +27 21 406 6492, Fax: +27 21 406 6411. Email: shurreta.thomas@uct.ac.za

Declaration by participant:

I……..do accept to give consent to take participate in the research study that has been explained to me by the research officer/research Assistant.

I agree and declare that:

I have also read and understood the consent form, or that it has well been read to me in a clear language that I understand and I am comfortable with.

I have also been given a chance to express myself freely, to ask any question or raise up any concern in regard to the study before, during and after the interview.

I have also been well informed that I can withdraw at any time if I feel like doing so as my participation is voluntary and that my withdrawal will not affect the services of my loved one.

There is no any pressure on me to take part in the study.

I have also been assured of total privacy and confidentiality.

Signed/ at …… on (date)…….

Signature/ Thumb print of Participant…… signature of witness…….

Appendix E: Information and consent forms (Tumbuka version)

Mutu wa kafukufuku: kukula Kwa Suzgo la aiwo wakupwererera walwali awo wakulwala nthenda yavifusi mwalutaluta. Kafukufuku wakuchitikira pa chipatala mu msumba wa Mzuzu ku Malawi.

Mazgo yakudankha

Ine zinalane ndine ***Richard Banda*** nkhugwira ntchito pa chipatala cha vifusi cha St John of God ga dokotala wa nthenda ya vifusi, ndipo pa nyengo yasono nkhusambira masambiro yakusazgirapo pa ntchito ya udokotala uwu, masambiro gha pachanya, Masitazi (masters) pa Sukulu ya university ya mu msumba wa Cape Town ku South Africa.

Sono nga nigawo limoza la masambiro agha nkwenera kupanga kafukufuku wakukhuzana na ivyo nkhusambira.

Gawo la kafukufuku uyu ndakunowa chomene chomene wanthu awo wakupwererera walwali wakulwala nthenda ya vifusi lutaluta, kwali wakulwazga wana panji walala wanthu awa wawe kuti walwazga walwali awa kwa myezi yitatu panji kunjuphira apo kwambura kulipilika kweni wakuvwira waka.

Usanga ndimwe yumoza wa awo wakupwererera wanthu awo wakupokera wovwiri ku chipatala cha vifusi cha SJOG ndimwe wakwenerera kutolapo lwande pa kafukufuku uyu, ndipo mukuchemeka kuchita mwanthenla, muli wakufwatuka kusankha wakuyoghoya nayo mwa wanthu awo nkhuchita nawo kafukufuku, Ghanaghanani na kulanguluka Pambere mundayambe kutolapo lwande panji yayi.Fwatukani pakufumba chilichose icho mukupulikiska yayi muuwapo winu mu mulimo uwu.

Chakulinga cha kafukufuku uyu

Nchakumanyikwa kale kuti kulwala nthenda ya vifusi mwalutaluta vikwizisya masuzgo yakula mu chikaya ndipo vikwizisya masuzgo ghanandi muchigawa chose.

Muno mu Malawi chomenechomene mu Msumba wa Mzuzu nkhuwona kuti pala munthu muli wa vifusi, wanthu wa kupwererera chomene za mulwali kweni wakuluwa chomene masuzgo gha wanthu awo wakupwererera walwali awa. Ichi chikupagisya kuti nkhaliro wa walwali wavifusi na wakupwererera uwe wakusuzga chomene, mwantheula chakulinga cha kafukufuku uyu ni kufufuza nakusanga masuzgo agho wakupwererera walwali wakusangana nawo, kweniso kulawisya vinthu Vinyake ivyo vikupangisya kuti masuzgo agha yawe ghakulu.kafukufuku munyake uyo wali kuchitapo pa vinthu ivyo vikupangisya kuti masuzgo agho wakupwererera walwali wa nthenda ya vifusi ya lutaluta ghakulege chomene, wali kusimikiza kuti vinthu ivi vilipo , sono kafukufuku uyu akukhumba kusimikizga usange ivyo

wakusanga vingayanana na umo vilili kuno ku Malawi.Ndipo Vinyake mwa ivyo wakasanga kuti vikupangisya kuti masuzgo gha nawo wakupwererera walwali awa ghakule chomene ni ivi:

Kukula kwa ulwali, Utali wa nyengo iyo wakulwazga wakukhala na mulwali, wovwili ugho wakulwazga wakupokera kufuma ku wabale na wabwezi, na Vinyake ivyo vingapasya kuti umoyo wa wakulwazga na mulwali uwe uweme panjiunono. Vyakusangika vya kafukufuku uyu viwovwilenge kusanga zinthowa izo zili na ukabani izo zingawovwila wakupwererera walwali mwaluwilo, kuchepesya masuzgo ghawo.

Kasi wovwili winu ngwakuti uli?

Pa kafukufuku uyu mwazamukhumbikwa kuzgola mafumbo maso na maso kufumira kwa ise.Mafumbo ghake ngakukhuza ukhaliro winu na mulwali kweniso masuzgo agho mukukumana nawo mumaghanoghano, mumakhaliro pa chikaya kweniso paumoyo winu wa zuwa na zuwa chifukwa cha ntchito yakulwazya mulwali wakulwara nthenda ya vifusi yikulu,ndondomeko yakuyoghoya ivyo mukujumphamo pazamuwa wazamba (wa Nesi) wawiri na dokotala yumoza pa malo ghachisisi apo wanthu wanyake wangamupulikani yayi ivyo mukuyoghoya, mwazamuchita mulimo ughu para mulwali winu wapokera wovwili. Para mwamara kuzgola mafumbo alipo paumaliro mwasangika kuti muli na Suzgo pa thupi pinu panji muli na maghaghano ghakumutimbanizgani tazamukumovwirani mwakwenerera.

Kutolapo lwande mwambura kuchichizgika

Kuzomera kuti mutolepo lwande pa kafukufuku uyu ni chisankho chinu kwambura kuchichizgika muli na ufulu kutolapo lwande panji yayi a nlipo para mwaona kuti nchakwenerera yayi kutolapo lwande vyazamukhuza avwilikwa mulwali yayi.

Pali uheni uliwose kwa imwe para mwatolapo lwande?

Phindu lake: pa kafukufuku uyu tizamugwirisya vinthu vyakumukhuwazgani yayi ndipo tichitenge chilichose kuti pawevye chakunanga umoyo winu. Ndipo usange pa nyengo yakufumbani mafumbo mwawona kuti vyapangisya kuti muwe na chitima, nkawa, phalani mwaluwiro kuti timovwireni Pambere mundawere. Kafukufuku uyu kwakuzirwa kwa mulwali pera yayi kweniso kwa imwe para tawona kuti namwe mukukhumbikwa ovwiri, kweniso awovwirenge pakupwererera mulwali na imwe wuwo pakusanga masuzgo na kusanga uvwiri wakwenerera.

Kusunga chisisi: mu kafukufuku uyu, uyo wakulongozga na wakumovwira wekha ndiwo wazamusunga nakugwirisya ntchito vyakusangika pa kafukufuku uyu. Musambizi wa ise

tazamufumba vinthu vekha ivyo vikukoleranako na chakulinga cha kafukufuku. Ndipo mu vyakulemba tazamugwirisya ntchito mazina ghinu yayi kweni manambara pera.

Kasi Pali malipiro?

Paumaliro pa kuchezga namwe tazakumupasani ndalama yayi kweni sopo zakuchapira khumi kumuwongani chifukwa cha nyengo na wovwiri winu pa kafukufuku uyu.

Usange Pali fumbo panji dandaulo la kukhwasyana na kafukufuku uyu khwasyanani na mulala wa kafukufuku uyu pa adilesi iyo yili pa chanya apo. Kuno ku Malawi mungakhwasyana na upu uwo ukalawira vya kafukufuku wa National Health Research Ethics Committee of Malawi, secretariate on (265) 0888344443, (265) 01726418 panji upu wakuwona vya kafukufuku ku Sukulu ya masambiro gha pa chanya ya Cape Town (+27) 2140664492, Fax +274066411 e-mail:

Chizomerezgo

Ine _____ nkhuzomera kutolapo lwande pa kafukufuku uyo wanilongosolera walala wake panji wawovwiri wawo.

Nkhuzomera na kusimikizga kuti:

Nawazga nakupulikisya ivyo vyalembeka mu mapepala agha/mu Fomu iyi, panjiso yawazgika makola kwa ine muchiyoghoyelo ichonkhupulika ndipo napulikisya.

Ndiposo napasika mwawi wakuyoghoya mwakumasuka, wakufumba mafumbo kweniso kuyoghoya chilichose chakukhuzana na kafukufuku uyu pakuyamba, mukatikati kweniso mpaka pa umaliro wa kufumbika mafumbo.

Naphalirika makola kuti Ningaleka kuzgola mafumbo nyengo yose chifukwa vyambula kuchichizgana ndipo kuleka kuzgola mafumbo vikhavasye yayi wovwiri ku Mulwali, mubale wane Nilije kuchichizgika kutolapo lwande pa kafukufuku uyu. Wanisimikizgiraso kuti wasungane chisisi pa ivyo niwaphalirenge.

Na sayina _____ kuno ku St John of God zuwa ili 10/10/2017.

Appendix F: UCT HREC approval letter

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E52-24 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 404 7682
Email: nosi.tsama@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

23 January 2018

HREC REF: 754/2017

A/Prof M Schneider
Alan J Flisher Centre for Public Mental Health
Department of Psychiatry
46 Sawkins Road
Rondebosch

Dear A/Prof Schneider

PROJECT TITLE: PREVALENCE AND ASSOCIATED FACTORS OF CAREGIVING BURDEN AMONG CAREGIVERS OF INDIVIDUALS WITH SEVERE MENTAL ILLNESS: A HOSPITAL BASED STUDY IN MZUZU MALAWI (MPHIL CANDIDATE - MR R BANDA)

Thank you for submitting your response letter to the Faculty of Health Sciences Human Research Ethics Committee dated 06 December 2017.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30th January 2019.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

We acknowledge that the student Mr R Banda will be involved in this study.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval before the research may occur.

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Yours sincerely

Signature Removed

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Appendix G: NHSRC Malawi

Telephone: + 265 789 400
Facsimile: + 265 789 431

All Communications should be addressed to:

The Secretary for Health and Population

In reply please quote No.

.....

MINISTRY OF HEALTH AND POPULATION
P.O. BOX 30377
LILONGWE 3
MALAWI

27th February, 2018

Richard Banda
University of Cape Town/St John of God
Mzuzu

Dear Sir/Madam,

RE: Protocol 18/02/1980: Prevalence and Associated Factors of Caregiving Burden among Caregivers of Individuals with Severe Mental Illness: A Hospital-Based Study in Mzuzu, Malawi

Thank you for the above titled proposal that you submitted to the National Health Sciences Research Committee (NHSRC) for review. Please be advised that the NHSRC has **reviewed** and **approved** your application to **conduct** the above titled study.

- **APPROVAL NUMBER : 1980**
- The above details should be used on all correspondences, consent forms and documents as appropriate.
- **APPROVAL DATE : 27/02/2018**
- **EXPIRATION DATE**
  This approval expires on **26/02/2019**. After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the NHSRC Secretariat should be submitted one month before the expiration date for continuing review.
- **SERIOUS ADVERSE EVENT REPORTING:** All serious problems having to do with subject safety must be reported to the NHSRC within 10 working days using standard forms obtainable from the NHSRC Secretariat.
- **MODIFICATIONS**: Prior NHSRC approval using forms obtainable from the NHSRC Secretariat is required before implementing any changes in the protocol (including changes in the consent documents). You may not use any other consent documents besides those approved by the NHSRC.
- **TERMINATION OF STUDY**: On termination of a study, a report has to be submitted to the NHSRC using standard forms obtainable from the NHSRC Secretariat.
- **QUESTIONS**: Please contact the NHSRC on phone number *+265 888 344 443* or by email on mohdoccentre@gmail.com.
- **OTHER**: Please be reminded to send in copies of your final research results for our records (Health Research Database).

SECRETARY FOR HEALTH
2018 -02- 27
P.O. BOX 30377
CITY, LILONGWE

Kind regards from the NHSRC Secretariat.

Signature Removed

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For: **CHAIRPERSON, NATIONAL HEALTH SCIENCES RESEARCH COMMITTEE**
Promoting Ethical Conduct of Research[1]

Appendix H: Clearance Letter to Saint John of God Hospitaller Services

Alan J Flisher Centre for Public Mental Health
Department of Psychiatry and Mental Health
University of Cape Town
46 Sawkins Road, Rondebosch, 7700
Cape Town, South Africa

The Director of Services
Saint John of God Hospitaller Services
P.O. Box 744, Mzuzu
Malawi.
30th January 2018.

Dear Sir,

REF: APPLICATION FOR PERMISSION TO CONDUCT A STUDY AT YOUR INSTITUTION.

I write to seek permission to conduct a study at your institution titled *Prevalence and associated factors of caregiving burden among caregivers of individuals with severe mental illness*: *A Hospital based study in Mzuzu Malawi.*

I am currently pursuing my post graduate studies with the UCT for the Master of Philosophy in Public Mental Health (MPhil PMH). As a requirement for the award of the degree, I am supposed to conduct a research study.

The focus of my study is on caregivers of individuals (both children and adults) with severe forms of mental illness (SMI). The study is aiming at investigating prevalence and associated factors of SMI among caregivers of individuals with SMI at St John of God Hospitaller Services in Mzuzu Malawi.

Findings derived from the study are expected to assist in the establishment of the needs of caregivers with their care recipients. The study is also expected to help in the development of evidence based recommendations for the improvement of the mental health and quality of life of caregivers including their care recipients.

All ethical principles will be followed and adhered to. Caregivers found with psychological or other mental health related issues, will be assisted accordingly. Proper referrals will be made for the interventions.

Attached is an ethical clearance letter from the UCT Human Research Ethics Committee; HREC REF: 754/2017.

For more information, contact the undersigned or supervisors that appear in the proposal: See appendix E.

Your favourable consideration will be highly appreciated.

Yours faithfully,

Signature Removed

Richard Banda.

Student ID number: BNDRIC007
Email: richardbanda45@gmail.com
Mobile: (+265) 888 39 40 94
: (+265) 999 19 70 45

Appendix I: Clearance letter to conduct a research at SJOGHS

Saint John of God Hospitaller Services

Registered company under Companies Act 1984

2nd February, 2018

Richard Banda
St John of God Hospitaller Services
P.O. Box 744
Mzuzu

Dear Sir,

RE: PERMISSION TO CONDUCT RESEARCH WITHIN ST. JOHN OF GOD HOSPITALLER SERVICES.

Your earlier communication requesting permission to conduct research within St. John of God Hospitaller Services refers.

I am pleased to grant you permission to carry out the said exercise subject to the following conditions:-

- Participants will be facilitated to understand the purpose of your study, their personal involvement in the study and involvement of other people/groups
- Consent of participants will be sought before participation in the study – the participants will also be given freedom to withdraw during any stage of the study.
- Participants will be assured of confidentiality e.g. their identity and views.

Would you need any clarification on any of the above, feel free to contact the undersigned.

Wishing you the very best in your research project.

Faithfully yours,

Signature Removed

Charles Masulani
DIRECTOR OF SERVICE

P.O. Box 744 **Tel:** 265 (0) 1 311 495 **Fax:** 265 (0) 1 311 213 **Email:** sjog@sjog.mw **Web:** www.sjog.mw
Katoto, **Mzuzu**,
Malawi

Appendix J: Map of Malawi